

HOUSE OF LORDS

Select Committee on HIV and AIDS in the
United Kingdom

1st Report of Session 2010–12

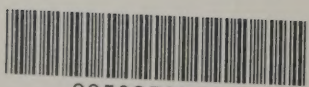
**No vaccine, no cure:
HIV and AIDS in
the United
Kingdom**

Report

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HL Paper 188



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HOUSE OF LORDS
Committee Office

House of Lords
London
SW1A 0PW

Tel: 020 7219 4827
Fax: 020 7219 4931
daviesma@parliament.uk
www.parliament.uk/lords

DIRECTOR'S OFFICE

1 SEP 2011

1 September 2011

No vaccine, no cure: HIV and AIDS in the United Kingdom

I am pleased to enclose a copy of the Report of the Select Committee, which is published today, 1 September 2011. I would like to express my gratitude for your contribution to the Committee's inquiry. I hope that the report and its conclusions and recommendations will be of interest to you.

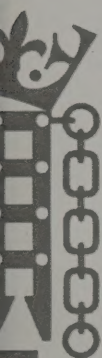
Copies of the report are also being sent to the UK Government. They are expected to send an official response to the report. Once this response has been considered by the Committee, it will be published on the House of Lords website.

The report has been made for debate, meaning that it will be discussed in the House of Lords in due course – details of this discussion will be posted on the Committee's website when they are known.

Thank you once again for your interest in, and contribution to, this inquiry.

Yours sincerely

Mark Davies
Clerk



HOUSE OF LORDS

Select Committee on HIV and AIDS in the
United Kingdom

1st Report of Session 2010–12

No vaccine, no cure: HIV and AIDS in the United Kingdom

Report

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Select Committee on HIV and AIDS in the United Kingdom

The Committee was appointed by the House of Lords on 20 December 2010 "to consider HIV and AIDS in the United Kingdom".

Membership

Lord Fowler (Chairman)
Lord Gardiner of Kimble
Baroness Gould of Potternewton
Baroness Healy of Primrose Hill
Baroness Hussein-Ece
Lord McColl of Dulwich
Baroness McIntosh of Hudnall
Baroness Masham of Ilton
Lord May of Oxford
Lord Rea
Baroness Ritchie of Brompton
Baroness Tonge

Declaration of Interests

See Appendix 1

A full list of Members' interests can be found in the Register of Lords' Interests:

<http://www.parliament.uk/mps-lords-and-offices/standards-and-interests/register-of-lords-interests/>

Publications

All publications of the Committee are available on the internet at:

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General Information

General information about the House of Lords and its Committees, including guidance to witnesses, details of current inquiries and forthcoming meetings is on the internet at:

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Committee Staff

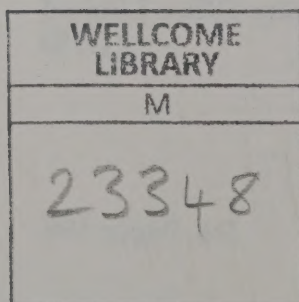
The current staff of the Committee are Mark Davies (Clerk), Matthew Smith (Policy Analyst) and Deborah Bonfante (Committee Assistant).

Contact Details

All correspondence should be addressed to the Clerk of the Select Committee on HIV and AIDS in the United Kingdom, Committee Office, House of Lords, London SW1A 0PW

The telephone number for general enquiries is 020 7219 4827.

The Committee's email address is holhivandaids@parliament.uk



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NOTE:

Evidence is published online at www.parliament.uk/hivselect and available for inspection at the Parliamentary Archives (020 7219 5314)

References in footnotes to the Report are as follows:

- Q refers to a question in oral evidence;
- HAUK 1 refers to written evidence as listed in Appendix 2.

SUMMARY

Awareness of HIV and AIDS in Britain has fallen below the public radar. In the late 1980s, following the *Don't Die of Ignorance* campaign, public awareness of the disease was very high. Today the common question asked is—'Is it still a problem?' Perhaps because the scale of the epidemic in Africa is so vast, the undoubted challenge here is pushed to one side. Yet HIV in Britain has not gone away. In recent years, in fact, the number of new diagnoses has been more than double the annual rate seen in the mid-1990s.

By next year there will be over 100,000 people living with the disease. The number of patients has trebled in the last ten years and there is increasing pressure on the health service in dealing with our epidemic. Just as seriously, it is estimated that over a quarter of those living with HIV do not know of their condition. This not only has serious consequences for the individual because treatment is delayed, but also means that the infection is likely to be spread further.

Twenty-five years on from the 1986 campaign there is still no vaccine and, although antiretroviral drugs have dramatically cut the death toll, there is still no cure. These drugs make it possible to successfully live with HIV, but they are also the main reason why the cost of treatment for this entirely preventable disease is now approaching £1 billion a year.

This report examines what is necessary to tackle the epidemic in this country. We believe above all that a new priority must be given to prevention. The advice of the 1980s—on using a condom, on reducing numbers of sexual partners and on not using contaminated needles—remains good today. We argue for a new national campaign to raise public awareness generally, but stress that this is only one part of a general prevention policy.

Prevention measures have already showed their worth. The 1986 campaign, alongside a concerted effort within the gay community, led to a drop in HIV infections and sexually transmitted infections generally; the introduction of needle exchange programmes has meant that in Britain the rate of transmission amongst injecting drug users has remained consistently low compared to a number of other countries; and routine antenatal testing of pregnant women has meant that very few babies are now born with HIV. If new infections can be prevented, then the results are beneficial both in human terms and in savings for the health service, with a lifetime of treatment estimated to cost between £280,000 and £360,000.

In developing a new prevention policy, better testing is a priority. It is in no one's interest that there should be so many people living with undiagnosed HIV. New efforts need to be made to diagnose those infected as early as possible. Tests for pregnant women are now on an 'opt-out' basis, meaning that they will be carried out automatically unless there is an objection. This has been a significant success, and we believe that a sensible next step would be to introduce similar arrangements for all new patients at GP surgeries and general medical admissions, starting in high-prevalence areas.

Our aim is to break down the barriers that stand in the way of people coming forward for testing. For that reason, we propose that testing should go beyond the traditional settings of genitourinary medicine and antenatal clinics. We need to further encourage testing by general practitioners, and ensure that they take a full part in the efforts to reduce HIV. We also propose the legalisation and regulation of home testing.

It is also vital that the stigma and discrimination—based at best on ignorance, and at worst on prejudice—which still surrounds HIV is eliminated. Our evidence shows that even today there are cases of graffiti being sprayed on the houses of people living with HIV. Such acts of discrimination prevent those with HIV coming forward for testing, with serious consequences both for the individual and for public health generally.

We praise the invaluable help of voluntary organisations in tackling HIV, and urge that this should be recognised by the Government and local authorities when they take on greater responsibility for public health. We believe that the Government's proposals for a national public health service with a ring-fenced budget holds great opportunities—but also contains risks that must be avoided. In particular, with HIV services set to be commissioned at both national and local levels, safeguards must be put in place to ensure that HIV is not lost amidst the many competing demands incumbent upon commissioners. We are also concerned that the crucial role that local Directors of Public Health play should be properly recognised.

Traditionally, sexual health has been the poor relation of the health service. Its position is symbolised by the fact that sexual health clinics are too often placed at the very rear of the hospital. We recognise the enormous spending on treatment and care (which also helps in prevention), but deplore the lack of resources devoted to prevention work more generally. Prevention represents the very best investment that any government can make. It can yield significant savings by avoiding future treatment costs which on present projections will inevitably increase. It is only through an effective and coordinated prevention policy that we will start to arrest the numbers of people living with HIV in the United Kingdom, and give proper priority to tackling this disease.

No vaccine, no cure: HIV and AIDS in the United Kingdom

CHAPTER 1: AN INTRODUCTION

1. Twenty-five years ago, a major campaign was launched to tackle HIV and AIDS in the United Kingdom. At the time there was no effective treatment for the disease; AIDS was usually a death sentence. It was already making devastating inroads in Africa and seriously affecting several cities in the United States, such as San Francisco and New York. The question for the Government was what measures could be taken to prevent the spread of the virus here. The decision taken was that the main measure should be public education, warning of the dangers and advising of the actions to take to avoid contracting the disease.
2. The result was one of the biggest public health campaigns ever seen. Leaflets were sent to 23 million homes under the banner: “AIDS—DON’T DIE OF IGNORANCE”. Posters were put up nationwide, telling the public that: “AIDS IS NOT PREJUDICED—IT CAN KILL ANYONE”. Under each was the additional message: “Gay or straight, male or female, anyone can get AIDS from sexual intercourse. So the more partners, the greater the risk. Protect yourself. Use a condom”.
3. At the same time the BBC and Independent Television produced radio and television programmes of their own warning of the dangers; and newly formed organisations like the Terrence Higgins Trust¹ and Body Positive worked to influence both behaviour in the gay community² and policy itself.³ Inside Government a special Cabinet committee was formed, which took a crucial decision to authorise the introduction of clean needle exchanges for drug users, with the aim of preventing a further source of transmission.
4. The net effect of these actions was that knowledge of the causes of HIV and AIDS vastly increased, with follow-up research showing that 98% of the public became aware of how HIV was transmitted.⁴ It was also shown that the vast majority of the country thought it was right to run such a campaign—in spite of fears that the material used was too explicit and would cause offence.⁵ The clean needle exchanges established their worth very early and have remained an instrument of policy ever since. Combined with awareness campaigns and behaviour change amongst the gay community, the result was a significant fall in HIV transmission among men who have sex with men (MSM)⁶ and similar reductions in other sexually transmitted infections such as gonorrhoea.⁷
5. That was the position at the end of the 1980s, but what is the situation in the United Kingdom today? There has been no nationwide campaign on the

¹ See Appendix 8 (Glossary)

² HAUK 24 (NAM).

³ HAUK 72 (Virginia Berridge).

⁴ COI/Gallup survey, March 1987

⁵ COI/Gallup survey, February 1987.

⁶ Sex Transm Inf 2001; 77: 242–247

⁷ Health Protection Agency, Sexually transmitted infection data tables, 2009:
http://www.hpa.org.uk/web/HPAwebFile/HPAweb_C/1204619477126

same scale since and, perhaps because of this, there is a widespread assumption that the danger has gone away.⁸ Nothing could be further from the truth. Thousands of people are still being infected every year.⁹ The numbers of those diagnosed with HIV continues to grow relentlessly and next year it is estimated that there will be 100,000 people living with HIV in the United Kingdom¹⁰, with the cost to the health service approaching £1 billion a year.¹¹ The numbers of those accessing care have trebled since 2000.¹² It remains one of the most serious public health issues confronting the Government at the start of the 21st century.

6. The nature of the challenge, however, has changed profoundly in one respect. In the 1980s AIDS was untreatable and too often a death sentence. Thanks to the utterly beneficial development of antiretroviral drugs, progression from HIV to AIDS can now be significantly delayed and life expectancy significantly improved—depending upon how quickly the condition is detected. There have been almost 20,000 deaths from AIDS in the United Kingdom since the epidemic began, with the peak being reached in 1995 when more than 1,700 people lost their lives.¹³ Thanks to the new drugs the number of deaths now run at around 500 a year, a number which has remained stable for the last decade.¹⁴ HIV has been transformed into a serious long-term condition for those who are infected, with just as serious cost consequences for the health service.
7. One assumption is that because of these medical advances, acquiring HIV is consequence-free. This is not remotely the case. We have been struck by the evidence given to us of the serious medical and mental health problems that remain for many with HIV.¹⁵ Many feel themselves isolated because of their condition¹⁶, and the issue of stigma has been constantly raised.¹⁷ The vast medical advances should not, therefore, breed a false sense of security. Patients can now live with HIV, but all those infected would prefer to be without a disease which can still cut short life and cast a shadow over their everyday living.
8. The cost of the epidemic continues to grow. Gross expenditure on HIV and AIDS increased by more than 50% in the four years between 2006/7 and 2009/10, rising from £500m to more than £760m.¹⁸ If the 3,800 infections acquired in this country which were diagnosed in 2010 had been prevented, £1.2bn in direct lifetime healthcare costs would have been avoided.¹⁹ These

⁸ See, for example, Q 595 (Natika Halil, FPA).

⁹ See QQ 833–834 (Dr Valerie Delpéch, HPA) and Q 837 (Professor Noel Gill, HPA).

¹⁰ HAUK 68 (Health Protection Agency).

¹¹ The cost of treatment and care was 762m in 2009–10, up from £500m in 2006–7: Department of Health, Programme Budget 2009–10: http://www.dh.gov.uk/en/managingyourorganisation/financeandplanning/programmebudgeting/DH_075743

¹² Health Protection Agency, *HIV in the United Kingdom (2010 Report)*: http://www.hpa.org.uk/web/HPAwebFile/HPAweb_C/1287145367237

¹³ Health Protection Agency, United Kingdom; new HIV diagnoses data to end of December 2010, Tables. No. 2, 2010.

¹⁴ *ibid.*

¹⁵ See, for example, Q 501 (Dr Simon Barton), and QQ 275–276 (Dr Ian Williams).

¹⁶ See, for example, Q 550 (Jim Jewers).

¹⁷ See, for example, HAUK 37 (Positively UK), HAUK 47 (National AIDS Trust), HAUK 22 (Body and Soul).

¹⁸ Department of Health, Programme Budget 2009–10, *op. cit.*

¹⁹ HAUK 97 (Health Protection Agency).

costs will only increase as the numbers of those living with HIV rise; increasing life expectancy means that treatment lasts for decades rather than years.

9. This is *not* a case for cutting back on treatment; it is a case for investing in prevention. HIV remains an entirely preventable condition, unlike other expensive conditions like asthma.²⁰ Investment in preventing future infections has the potential to ensure huge savings in future costs. We are concerned that successive governments have seemed unable to grasp this essential point. The result is that the number of new infections, which could have been prevented, have risen; and health service costs, which could have been avoided, have increased. HIV and AIDS has not been given the priority it deserves.
10. In their planned changes to the National Health Service the Government have proposed significant changes to how public health services are organised. This includes the creation of a dedicated public health body, Public Health England, with its own ring-fenced budget. These changes hold the potential for significant improvement. The acid test will be the response to the challenge of HIV and AIDS.
11. The Committee was appointed by the House of Lords on 20 December 2010 to consider “HIV and AIDS in the United Kingdom”. The aim of this report is to examine progress made in tackling the domestic HIV epidemic over the past 25 years, and, where appropriate, to propose recommendations to move the situation forward.
12. Health is a devolved issue. This is most important in considering the potential impact, as we do, of proposed NHS and public health reforms. Many of those reforms extend only to England. It is therefore inevitable that many of our recommendations will not be applicable nationwide. However, where they are of more general relevance, we hope that the recommendations can be instructive throughout the United Kingdom.
13. We took evidence from a diverse range of witnesses between January and June 2011, including clinicians, vaccine researchers, prevention experts, people living with HIV and faith and community groups. This work has been supplemented by visits to HIV clinics and community centres in London, Brighton and Leeds, as well as a visit to Her Majesty’s Prison Brixton. We have been assisted in our work by Professor Anne Johnson, Co-Director of the University College London Institute for Global Health. We would like to express our thanks for the support provided by Professor Johnson as Specialist Adviser to the Committee.

²⁰ Gross expenditure on asthma was more than £1bn in 2009–10: Department of Health, Programme Budget 2009–10, *op. cit.*

CHAPTER 2: THE SCALE OF THE CHALLENGE

14. Human immunodeficiency virus (HIV) is a transmissible virus which targets white blood cells in the body, affecting the immune system. While it is predominantly sexually transmitted, it can also be spread through the sharing of injecting drug equipment, transmission from mother to child and through contaminated blood and blood products. Unlike other sexually transmitted infections (STIs), HIV cannot be cured. There is no vaccine to protect against HIV. It is a lifelong, potentially life-threatening condition. Untreated, HIV leaves an infected person more vulnerable to serious infections and some cancers; and if a person develops one or more of a specified range of these illnesses²¹, they are said to have progressed to Acquired Immunodeficiency Syndrome (AIDS), which was first described in 1981.
15. The success of the response to HIV and AIDS in the 1980s was based partly on the profile of HIV and AIDS in the public mind. Although HIV no longer has that same prominence, the problem is more extensive and widespread than ever before. There were an estimated 86,500 people living with HIV at the end of 2009, the latest year for which figures are available.²² By next year, this figure is likely to surpass 100,000.²³
16. Disturbingly, many of those living with HIV do not know that they are infected. Surveillance systems operated by the Health Protection Agency (HPA)²⁴ use anonymised blood samples from a number of sources to estimate this 'undiagnosed fraction'.²⁵ The HPA estimated that 26 % of those living with the virus in 2009—more than 22,000 people—had not been diagnosed.²⁶ Those undiagnosed are not receiving treatment and support which could both improve their health and significantly reduce the chances of them passing on the virus. Despite increased levels of testing, leading to an increase in the prevalence of diagnosed infections, the prevalence of undiagnosed HIV has not changed significantly in the last 10 years.²⁷
17. There has also been a dramatic increase in the yearly number of new HIV diagnoses since the late 1990s. This peaked in 2005, with more than 7,800 new diagnoses (see Figure 1).²⁸ In 2010, there was a year-on-year increase for the first time since then, with an estimated 6,750 people diagnosed.²⁹ At the same time, the impact of antiretroviral therapy has led to a significant decline in the numbers of people progressing from HIV to AIDS.³⁰

²¹ These conditions are known as AIDS-defining illnesses.

²² Health Protection Agency, *HIV in the United Kingdom (2010 Report)*, *op. cit.*

²³ HAUK 68 (Health Protection Agency).

²⁴ See Appendix 8.

²⁵ HAUK 97 (Health Protection Agency)—“The estimates of undiagnosed infections rely on data from unlinked anonymous (UA) serological surveys conducted in four selected adult populations: pregnant women, injecting drug users attending drug agencies, sexual health clinic attendees tested for syphilis and MSM attending community venues recruited through the Gay Men’s Sexual Health Survey (conducted in collaboration with University College London).”

²⁶ Health Protection Agency, *HIV in the United Kingdom (2010 Report)*, *op. cit.*

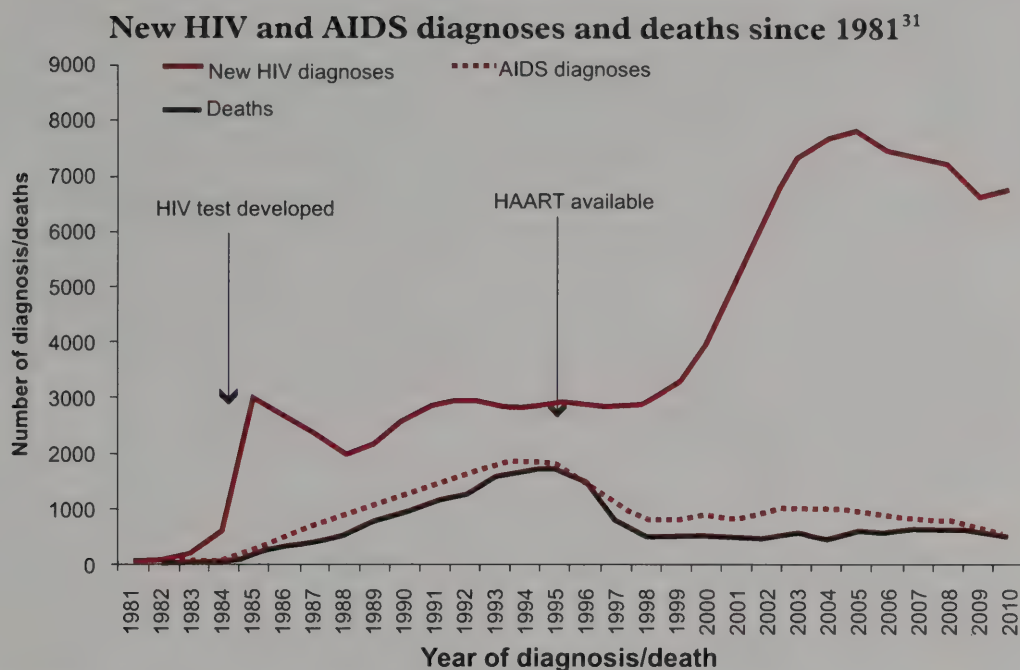
²⁷ HAUK 97 (Health Protection Agency).

²⁸ Health Protection Agency, United Kingdom; New HIV diagnoses data to end of December 2010, *op. cit.*

²⁹ *ibid.*

³⁰ *ibid.*

FIGURE 1



Source: Health Protection Agency, Health Protection Report Vol 5 No 22; 6 June 2011:
<http://www.hpa.org.uk/hpr/archives/2011/news2211.htm>

The newly infected

18. Increasing numbers of new diagnoses in part reflect efforts to increase levels of HIV testing. However, as infections are often not diagnosed for a number of years³², the number of people diagnosed in a given year does not indicate how many people actually acquired their infection in that year—a measure known as the incidence. Calculating this is a more difficult process, but the HPA uses a number of statistical processes in an attempt to do so.³³
19. Dr Valerie Delpech, Consultant Epidemiologist and Head of National HIV Surveillance at the HPA, estimated that around 3,000 new infections occur amongst MSM per year.³⁴ A quarter of MSM newly diagnosed in 2010 probably acquired their infection in the four to five months prior to diagnosis, with higher recent rates amongst younger age groups.³⁵ For heterosexual men and women, Dr Delpech suggested that each year there were at least 300 to 400 new infections³⁶; Professor Noel Gill, Head of the HIV and STI Department in the National Infectious Disease Surveillance Centre of the HPA, estimated the true figure to be around 1,000.³⁷ Although new diagnoses are not the same as new infections, the numbers of each appear to be broadly equivalent: in 2010, there were 3,080 new diagnoses amongst MSM, and 1,150 new heterosexual diagnoses acquired in the United Kingdom.³⁸

³¹ Note: In this figure, HAART refers to 'highly active antiretroviral therapy'.

³² See, for example, Q 833 (Dr Valerie Delpech) and Q 839 (Professor Noel Gill).

³³ See HAUK 97 (Health Protection Agency). Such techniques use new diagnosis levels, CD4 counts (see Appendix 8), undiagnosed fraction estimates and recent infection algorithm data to produce an estimate of those infected each year. See also Q 833 (Dr Valerie Delpech).

³⁴ Q 833.

³⁵ Health Protection Agency, Health Protection Report Vol 5 No 22; 6 June 2011.

³⁶ Q 834.

³⁷ Q 837.

³⁸ Health Protection Agency, United Kingdom; New HIV diagnoses data to end of December 2010. *op. cit.*

Who has HIV?

Groups at highest risk

20. In the United Kingdom, two groups—MSM and those from black African communities—are at highest risk of acquiring HIV. Of those diagnosed in 2010, just over 3,000 (45%) were MSM, and just over 1,700 (26%) identified as black African.³⁹ The majority of infections diagnosed in 2010 amongst MSM were acquired within the United Kingdom, whereas the majority of those newly diagnosed in the black African community were infected abroad.⁴⁰ Of those diagnosed with HIV and seen for care in 2009 (the latest year for which figures are available), 43% were MSM, and 33% were from black African communities.⁴¹
21. Those two groups, however, are not the only ones at risk. More than 11,300 people from outside black African communities, who acquired their infection through heterosexual sexual contact within the United Kingdom, accessed care in 2009.⁴² The same group accounted for around 700 cases of UK-acquired infections diagnosed in 2010.⁴³ Sharing of injecting drug equipment and mother-to-child transmission are also means by which infection can spread, but both make up a small proportion of overall cases. Only 160 people who acquired HIV through injecting drug use were diagnosed in 2010⁴⁴, and only 5,500 people have been so diagnosed since the epidemic first emerged in 1981.⁴⁵ Similarly, only 77 cases of mother-to-child transmission were diagnosed in 2010, with fewer than 2,000 diagnoses since 1981.⁴⁶

Age range

22. The age profile for HIV diagnoses is older than for STIs generally. Young people accounted for 57% of those diagnosed with the five most common STIs⁴⁷ in England in 2009.⁴⁸ In the same year, 10% of diagnoses for HIV were amongst those aged between 15 and 24 years old⁴⁹, whilst half of those diagnosed were aged between 25 and 40.⁵⁰ The older profile is partly due to the often long delay between infection and diagnosis.
23. A mixture of late diagnosis, continuing sexual activity and increased life expectancy for those infected also means that there is an increasing number of those aged over 50 being diagnosed with HIV. New diagnoses amongst that group doubled in the previous decade, accounting for 13% of all diagnoses in 2009.⁵¹ It must be stressed, though, that increasing numbers of diagnoses are being made across all age groups.⁵²

³⁹ *ibid.*

⁴⁰ *ibid.*

⁴¹ Health Protection Agency, *HIV in the United Kingdom (2010 Report)*, *op. cit.*

⁴² *ibid.*

⁴³ Personal correspondence with the Health Protection Agency.

⁴⁴ Health Protection Agency, United Kingdom: New HIV diagnoses data to end of December 2010, *op. cit.*

⁴⁵ Health Protection Agency, Health Protection Report, 6 June 2011, *op. cit.*

⁴⁶ Health Protection Agency, United Kingdom: New HIV diagnoses data to end of December 2010, *op. cit.*

⁴⁷ Chlamydia, herpes, warts, gonorrhoea and syphilis.

⁴⁸ HAUK 97 (Health Protection Agency).

⁴⁹ HAUK 68 (Health Protection Agency).

⁵⁰ Health Protection Agency, United Kingdom: New HIV diagnoses data to end of December 2010, *op. cit.*

⁵¹ Health Protection Agency, *HIV in the United Kingdom (2010 Report)*, *op. cit.*

⁵² See Health Protection Agency, United Kingdom: New HIV diagnoses data to end of December 2010, *op. cit.*

National spread

24. HIV infection is a problem nationwide, but it is concentrated in certain urban and metropolitan centres. This is particularly so in London: of more than 65,000 people accessing care for HIV in 2009, over 28,000 (more than 40%) were based in London.⁵³ In the London Borough of Lambeth alone, the area with the highest prevalence of HIV in England, more than 2,700 people accessed care for HIV in 2009.⁵⁴ Other urban centres, such as Manchester and Brighton, also have a comparatively high prevalence of HIV.⁵⁵

The dangers of late diagnosis

25. Late diagnosis is one of the most serious problems we face.⁵⁶ The timeliness of a diagnosis is measured in relation to the levels of a particular type of white blood cell, CD4+, in the blood (the CD4 count⁵⁷). This is because HIV attacks the body's immune system, reducing levels of these cells in the body.⁵⁸
26. Late diagnosis means that antiretroviral therapy has been delayed, which has grave health implications for the person diagnosed. There is a 10-times higher chance of dying within the first year after diagnosis⁵⁹, and life expectancy is 10 years lower compared to those receiving prompt treatment.⁶⁰ Of those who died because of HIV during 2009, 73% had been diagnosed late.⁶¹ Delaying treatment misses a chance to reduce the risk of onward transmission (see para 175). It also means more complex⁶² and expensive⁶³ treatment for those diagnosed.
27. Early diagnosis is overwhelmingly in the interests of public health. Diagnosis allows access to treatment, which one study found reduced the transmission risk amongst heterosexual couples by as much as 96%.⁶⁴ Being diagnosed can also reduce risk behaviours amongst those infected.⁶⁵
28. In 2009, the latest year for which figures are available, 52% of adults diagnosed were diagnosed late, with a lower proportion of late diagnoses among MSM (39%) compared with heterosexual women (59%) and men (66%).⁶⁶ Late diagnosis is also a problem amongst those aged over 50, for whom two-thirds of diagnoses were late.⁶⁷

⁵³ Health Protection Agency, Survey of Prevalent HIV Infections Diagnosed (SOPHID), Data tables 2009: http://www.hpa.org.uk/web/HPAwebfile/HPAweb_c/1221482342808

⁵⁴ *ibid.*

⁵⁵ *ibid.*

⁵⁶ See, for example, QQ 235–236 (Dr Ian Williams and Dr Keith Radcliffe).

⁵⁷ See Appendix 8.

⁵⁸ When the CD4 count falls below the level at which treatment is recommended to begin (350 cells per mm³ of blood), the diagnosis is considered to be late. If the count falls further, to below the level at which treatment was recommended under previous guidelines (200 cells per mm³ of blood), the diagnosis is said to be very late (see Appendix 8).

⁵⁹ Q 32 (Dr Valerie Delpech).

⁶⁰ HAUK 53 (British HIV Association).

⁶¹ Health Protection Agency, *HIV in the United Kingdom (2010 Report)*, *op.cit.*

⁶² HAUK 64 (Terrence Higgins Trust), HAUK 47 (National AIDS Trust).

⁶³ HAUK 51 (London Specialised Commissioning Group), HAUK 36 (Association of Directors of Public Health), HAUK 67 (Health Protection Agency).

⁶⁴ Cohen MD *et al.*, *Prevention of HIV-1 infection with Early Antiretroviral Therapy*, New England Journal of Medicine, July 2011.

⁶⁵ Q 331 (Professor Mike Kelly), HAUK 50 (Halve It Coalition).

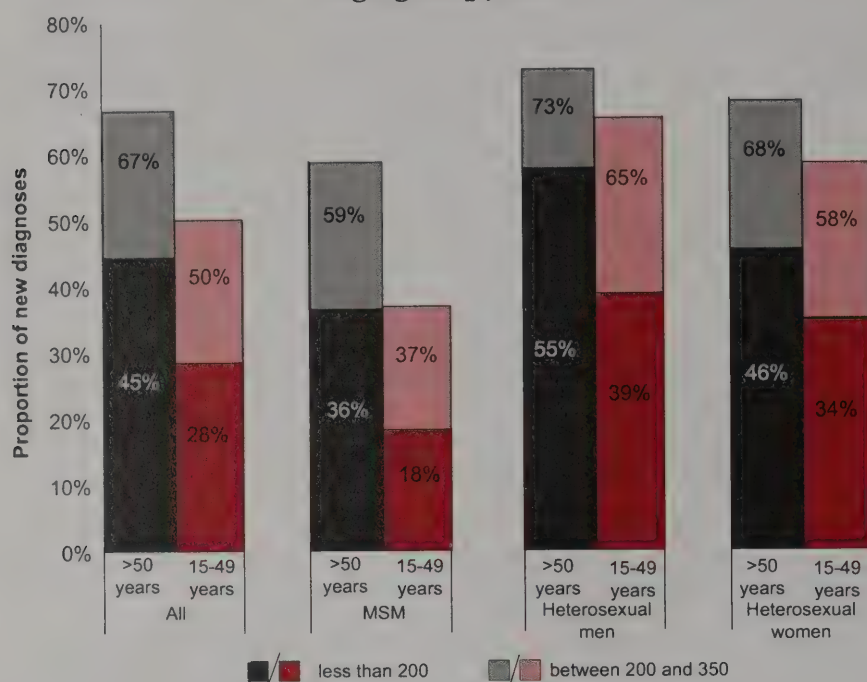
⁶⁶ Health Protection Agency, *HIV in the United Kingdom (2010 Report)*, *op.cit.*

⁶⁷ *ibid.*

29. A very late diagnosis⁶⁸ is of even greater concern, worsening the prognosis for the patient even further. Yet this was the case for 30% (nearly 2,000 people) of those newly diagnosed in 2009, a proportion again higher amongst heterosexual men and women.⁶⁹ Given that a late diagnosis indicates that a patient may have gone undiagnosed for up to eight years⁷⁰, this is deeply disturbing.

FIGURE 2

Late* and very late diagnosis of HIV Infection by prevention group and age group, 2009**



* Diagnosed with a CD4 cell count <350 per mm³ (within 91 days of diagnosis)

** Diagnosed with a CD4 cell count <200 per mm³ (within 91 days of diagnosis)

Source: Health Protection Agency, *HIV in the United Kingdom (2010 Report)*, op.cit.

How many are accessing care?

30. The number of those accessing treatment and care has trebled since 2000.⁷¹ Then, around 22,000 people were accessing care. In 2009, this had risen to more than 65,000.⁷² There are a number of reasons for this increase. Significant numbers of new diagnoses are being made each year. At the same time, those diagnosed have been living progressively longer as antiretroviral therapies have developed. A person diagnosed at age 20 can now be expected to live on average for a further 46 years—16 years longer than somebody in the same position in 1996.⁷³ Furthermore, changes in treatment guidelines, encouraging treatment at an earlier stage, meant that the proportion of those

⁶⁸ See footnote 59. See also Appendix 8.

⁶⁹ Health Protection Agency, *HIV in the United Kingdom (2010 Report)* op. cit.

⁷⁰ Q 32 (Dr Valerie Delphech).

⁷¹ Health Protection Agency, *HIV in the United Kingdom (2010 Report)*, op.cit.

⁷² *ibid.*

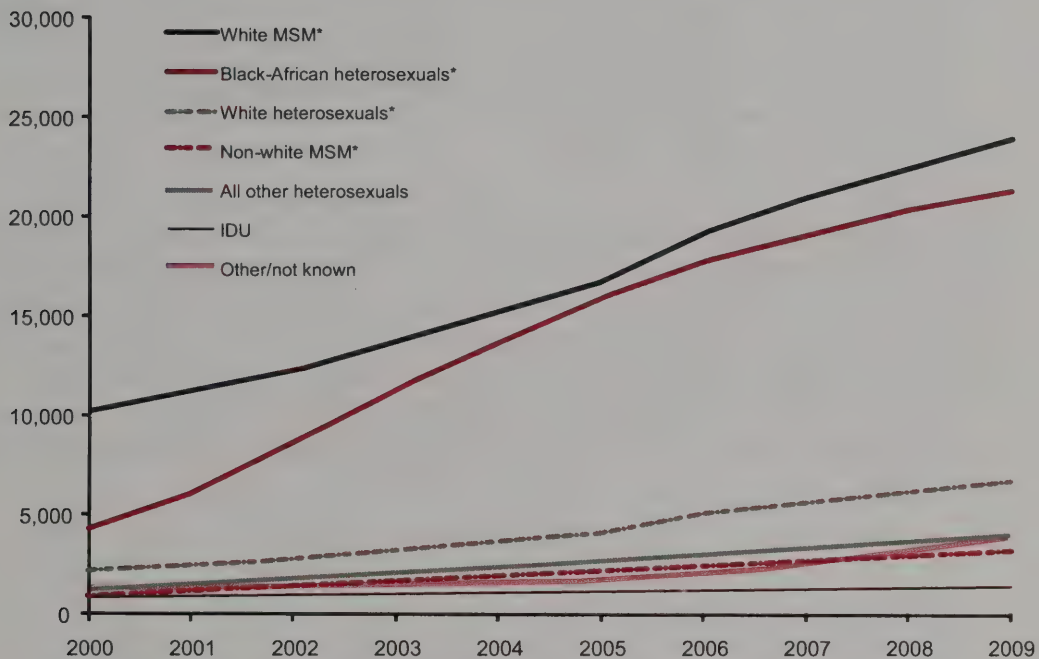
⁷³ May M et al., *Impact on life expectancy of late diagnosis and treatment of HIV-1 infected individuals: UK CHIC, 2010.*

accessing care who were receiving antiretroviral therapy increased from 70% in 2000 to 78% in 2009.⁷⁴

FIGURE 3

Cumulative numbers of those accessing care by prevention and ethnic group, 2000–2009

Diagnosed HIV-infected individuals seen for care by prevention group and ethnic group*, UK



* Excludes individuals with ethnicity not reported: 1,416 in 2000 and 934 in 2009

Annual survey of HIV infected persons accessing care

Source: Health Protection Agency, Numbers accessing HIV care, 2009 slide set:

http://www.hpa.org.uk/web/HPAweb&HPAwebStandard/HPAweb_C/1203064766492

The growing costs

31. The striking increase in the numbers of those accessing care has obviously impacted on the costs of providing treatment and care. Of the £1.9bn spent by the Government on infectious diseases in England in 2009/10, £762m (40%) was spent on the treatment of HIV and AIDS.⁷⁵ This spending included hospital services and drug prescriptions, but did not include spending on prevention or social care. It is also not clear, as the data cannot be separated out, how much of the cost of HIV testing is included.⁷⁶ Given these factors, the final total could be much higher.
32. Spending on HIV and AIDS has significantly increased over time, rising from an estimated £104m in 1997⁷⁷ to more than £500m in 2006/07.⁷⁸ Newer

⁷⁴ Health Protection Agency, *HIV in the United Kingdom (2010 Report)*, *op. cit.*

⁷⁵ Department of Health, Programme budget, 2009–10, *op. cit.*

⁷⁶ HAUK 94 (Department of Health).

⁷⁷ Mandalia *et al.*, *Rising Population Cost for Treating People Living with HIV in the UK, 1997–2013*, 2010

⁷⁸ Department of Health, Programme budget 2009–10, *op. cit.*

and more expensive drug regimes have contributed to this rise.⁷⁹ Given the high number of new diagnoses, the costs of HIV treatment are only likely to rise further over time.

Conclusion

33. HIV remains a very significant public health challenge. The number of people living with the virus continues to increase with no signs of halting. Thousands of new infections are occurring in the United Kingdom each year. Diagnosis, when it comes, is often late, whilst more than a quarter of those living with HIV simply do not know they are infected. This jeopardises the health of those infected, and is associated with continued risk of transmitting the virus to others. Meanwhile, increasing numbers of people accessing care drive up treatment costs in England towards £1bn. This makes HIV an increasing and increasingly expensive public health challenge which cannot be ignored. Tackling the issue should be a major priority for the Government.
34. **The Government should recognise the scale of the HIV and AIDS challenge in the United Kingdom. Not enough is being done to respond to a steadily growing risk to public health. There are potentially huge cost implications in both the short- and long-term in failing to deal effectively with the epidemic. At a time when public health in the United Kingdom is subject to major reform, the Government should ensure that HIV and AIDS is a key public health priority.**

⁷⁹ HAUk 82 (Sarah Stephenson, Greater Manchester Sexual Health Network), Q 724 (Simon Williams and Claire Foreman), Q 725 (Claire Foreman).

CHAPTER 3: NO VACCINE, NO CURE

35. Given the scale of the challenge, what can be done in response? The International AIDS Vaccine Initiative (IAVI)⁸⁰ noted that, “no other health intervention is more cost effective or has a greater impact on public health than vaccination”.⁸¹ In the last century, vaccines have delivered striking successes in the worldwide fight against diseases such as smallpox and polio.
36. The same was forecast for HIV. In 1984, the then United States Health Secretary, Margaret Heckler, said: “We hope to have a vaccine ready for testing in approximately two years ... yet another terrible disease is about to yield to patience, persistence and outright genius”.⁸² More than 25 years later, this pledge remains unfulfilled. Nonetheless, the development of a vaccine remains an important goal in the fight against HIV and AIDS.

No vaccine

37. In 2009, the latest year for which we received data, the main thrust of research worldwide came from the United States, through both public and charitable channels. The US National Institutes of Health dwarfed other funders, providing \$596m, whilst the Bill and Melinda Gates Foundation provided more than \$72m.⁸³ In comparison, funders based in the United Kingdom—the Government, the Medical Research Council (MRC) and the Wellcome Trust—provided \$23.6m between them.⁸⁴
38. Despite the dominant role of the United States, the United Kingdom has been an important partner. In 2009, the United Kingdom was Europe’s largest investor in HIV vaccine research, and the third largest funder worldwide.⁸⁵ Scientists based in the United Kingdom have also contributed significantly to the development of candidate vaccines. IAVI praised “UK leadership in the global arena”.⁸⁶ Professor Sir Andrew McMichael, Director of the Weatherall Institute of Molecular Medicine, noted that approximately half the MRC spend on HIV was relevant to vaccine development.⁸⁷
39. We applaud the commitment and leadership shown by successive governments in their support for the development of a HIV vaccine. Continuing commitment to the development of a vaccine is essential. This must continue to involve extensive international cooperation.
40. It is not only the public and philanthropic sectors, though, that can play a part in vaccine development. Pharmaceutical companies also have extensive expertise that could drive forward promising developments.⁸⁸ At present, they are not prominent within the field of HIV vaccine research. Professor Sir Andrew McMichael said that the “huge outlay, high risk of failure and impoverished markets” meant it was not an attractive area.⁸⁹

⁸⁰ A not-for-profit public-private partnership working to develop a vaccine for HIV.

⁸¹ HAUK 65.

⁸² Office of Technology Assessment ‘Review of the Public Health Service’s Response to AIDS’, U.S. Congress, Washington DC., February 1985, p29.

⁸³ HAUK 65 (IAVI).

⁸⁴ *ibid.*

⁸⁵ *ibid.*

⁸⁶ *ibid.*

⁸⁷ HAUK 14.

⁸⁸ Q 434 (Professor Sir Andrew McMichael).

⁸⁹ HAUK 14.

Mary Kerr, Vice-President and European Head of ViiV Healthcare⁹⁰, stressed that the complexity of HIV vaccine development, combined with a relative lack of capacity for HIV vaccine research within pharmaceutical companies, meant it was “not surprising that there has been a limited focus”.⁹¹

41. In light of these factors, the key question is how best to encourage participation. One model suggested was the Product Development Partnership, marrying public sector research with private sector product development⁹²; Mary Kerr and Lisa Bright, General Manager for UK and Ireland of Gilead Sciences⁹³, believed that a more streamlined approach to regulatory approval for clinical trials could also improve the situation.⁹⁴
42. The truth is, however, that the development of a vaccine is not likely in the short-term. Professor Sir Andrew McMichael stressed that there were “huge scientific obstacles” to overcome, and felt that a vaccine was at least a decade away.⁹⁵ Peter Weatherburn, Director of Sigma Research⁹⁶, noted that, “a vaccine has been five to six years away for at least 15 years ...”⁹⁷
43. **Funding bodies, both public and private, should continue to support HIV vaccine research as part of their research strategies. Cooperation with international partners must be central to this work. At the same time, the Government should consult with the pharmaceutical sector to determine whether improvements can be made to existing models of working and regulatory processes to better involve them in efforts to develop a HIV vaccine.**
44. **Although the successful development of a vaccine is crucial in the longer-term, the response to HIV and AIDS in the United Kingdom must be based on the assumption that none will exist for at least a decade.**

No cure

45. Another way to combat a disease is to cure a person affected by eradicating it from their body. This is not yet possible for HIV. The virus can be suppressed, but not eliminated, by existing therapies.⁹⁸ According to Professor Jonathan Weber, Director of Research for the Faculty of Medicine at Imperial College London, such eradication is “the grail” for HIV research.⁹⁹ Nevertheless, suppressive antiretroviral therapy has been an important part of the response to HIV (see Chapter 7). As Professor Sir Andrew McMichael said, “you cannot treat your way out of this pandemic, but you can do quite a lot of good with drug treatment as a holding measure”.¹⁰⁰

⁹⁰ A joint GlaxoSmithKline and Pfizer HIV pharmaceuticals venture.

⁹¹ Q 402.

⁹² HAUK 65 (IAVI), HAUK 71 (Professor Jonathan Weber).

⁹³ A pharmaceutical company.

⁹⁴ Both at Q 415.

⁹⁵ Q 444.

⁹⁶ A social research group, part of the Faculty of Public Health and Policy at the London School of Hygiene and Tropical Medicine.

⁹⁷ Q 906.

⁹⁸ Q 477 (Professor Jonathan Weber).

⁹⁹ Q 477.

¹⁰⁰ Q 443.

46. It is essential, though, that treatment does not cause longer-term harm. If a person fails to stick to a regime of antiretroviral drugs, it can lead to the development of drug resistance, as has been seen with antibiotics. Were such resistance to become widespread, treatment efforts would be hampered in the long-term. This is closely monitored. The United Kingdom has the largest resistance database linked to clinical data in the world, to ensure that any problems are quickly identified.¹⁰¹ With no vaccine and no cure, it is important that surveillance systems robustly monitor and contain the risk of emerging antiretroviral resistance (see paras 227 to 228).

Putting prevention first

47. Given the lack of either a vaccine or a cure, we must consider what else can be done to prevent the spread of HIV. Dr John Middleton, Vice-President of the United Kingdom Faculty of Public Health, noted that, “prevention is better than cure when there is no cure”.¹⁰²
48. At present, the priority given to prevention at national and local levels is woefully inadequate. Peter Weatherburn believed that HIV prevention was a “poor relation” within sexual health services.¹⁰³ This is demonstrated by the disparity in spending between HIV treatment and prevention. £2.9m will be spent on national prevention programmes in 2011/12.¹⁰⁴ This spending has been static since 2009/10, and is less than half a percent of the £762m spent on treatment and care in England in that year.¹⁰⁵ In London, treatment costs last year were around £250m¹⁰⁶, whilst Primary Care Trusts spent around £3m on prevention work, which included awareness campaigns and counselling, as well as one-to-one and group interventions.¹⁰⁷
49. This failure to invest persists despite evidence of the savings that prevention work could yield. The Health Protection Agency indicated that each infection prevented would save between £280,000 and £360,000 in direct lifetime treatment costs.¹⁰⁸ This means that if the estimated 3,800 UK-acquired HIV cases diagnosed in 2010 had been prevented, more than £32m annually, and £1.2bn in lifetime costs, would have been avoided.¹⁰⁹
50. Such stark figures demonstrate that there is no downside to investing in effective prevention, and no justification for the existing imbalance in spending. There are still thousands of new infections per year, which will increase the costs of treatment in the long-term. Current spending priorities commit the Government to ever-more expensive treatment costs without providing anywhere near enough resources to break the cycle. This must be rectified. Though we acknowledge elsewhere that diagnosing and treating those infected with HIV can have preventive effects which support broader prevention efforts (see para 175), more money should be devoted to

¹⁰¹ QQ 446–7 (Dr Sheena McCormack).

¹⁰² Q 832.

¹⁰³ Q 881.

¹⁰⁴ HAUK 19 (Department of Health).

¹⁰⁵ HAUK 94 (Department of Health).

¹⁰⁶ HAUK 51 (London Specialised Commissioning Group).

¹⁰⁷ Q 740 (Simon Williams) HAUK 19 (Sima Chaudhury) and personal correspondence with Mark Creelman, Inner North West London PCTs.

¹⁰⁸ HAUK 97 (Health Protection Agency).

¹⁰⁹ *ibid.*

preventing new infections through a range of interventions in addition to antiretroviral therapy.

51. We note the support for the prevention agenda from the Government. Professor David Harper, Director General for Health Improvement and Protection and Chief Scientist at the Department of Health, outlined that prevention was “absolutely at the heart of what we are saying and what we are trying to achieve.”¹¹⁰ Anne Milton MP, Minister for Public Health, stressed that “prevention remains as important as it did 25 years ago.”¹¹¹ Despite this, she believed that the question of resources was more about “how effectively that money is spent ...”¹¹²
52. The Government must match their words with action. Though money must of course be spent effectively (see para 93), the balance between money spent on the treatment of those infected and that spent on preventing people acquiring HIV is simply disproportionate. This must be rectified. More resources should be allocated to HIV prevention work, going beyond controlling the viral load of those infected. Such work should include testing and treatment for other STIs, as well as individual and group interventions to reduce risk behaviours amongst those who are HIV-positive or at high risk of infection, both within and outside clinical settings.
53. The Government have an opportunity to give this broader prevention work greater priority through the development of a new sexual health policy document. This will replace the previous (now-expired) sexual health strategy¹¹³, and the Minister indicated that the new document would have the same status and purpose as that strategy.¹¹⁴ This opportunity must be taken.
54. Funding for prevention should not, though, come at the expense of HIV treatment. As Peter Weatherburn said, “you cannot buy prevention instead of drugs”¹¹⁵; not least because of the important preventive role such treatment plays by suppressing levels of the virus in the body. Treatment and prevention work together; both must be fully supported by the Government if combating HIV and AIDS in this country is to be taken seriously.
55. **Further Government support for prevention is required. Prevention should be at the forefront of the response to HIV. This must be reflected in the Government’s replacement of the 2001 sexual health strategy. More resources must be provided at national and local levels. The Government should monitor and audit the use of resources so provided, to ensure they are used for the purpose of preventing new HIV infections.**

¹¹⁰ Q 167.

¹¹¹ Q 1089.

¹¹² Q 1090.

¹¹³ Department of Health, *Better prevention, better services, better sexual health—The national strategy for sexual health and HIV*, July 2001.

¹¹⁴ Q 1130.

¹¹⁵ Q 881.

CHAPTER 4: PREVENTION: GETTING THE MESSAGE ACROSS

56. The previous sections established that prevention should be a focus whilst there is no realistic prospect of either a vaccine or a cure for HIV. This is especially important given that the cumulative effect of year-on-year increases in the number of people living with HIV is that treatment costs will continue to rise, presenting an increasing burden for the NHS.
57. This chapter examines existing prevention activity, reflecting upon the effectiveness and resource base of such work, before setting out how prevention initiatives should be developed and improved.

Prevention campaigns—the current situation

National HIV programmes

58. Currently, nationally funded HIV prevention work is ‘targeted’ at the two groups most at risk of infection. Since 1996, the Department of Health has funded the Terrence Higgins Trust for a national prevention programme focused upon MSM; and since 2000, the Department has funded the African Health Policy Network (AHPN)¹¹⁶ for work with African communities living in England. For 2011/12, the Terrence Higgins Trust will receive £1.9 million, whilst the AHPN will receive £1 million.¹¹⁷
59. Terrence Higgins Trust and the AHPN work through partnerships which bring together a wide range of community and third sector groups to deliver locally specific HIV prevention activity. For MSM, this work is delivered through the Community HIV and AIDS Prevention Strategy (CHAPS), whilst for black African communities, activities and funding are delivered through the National African HIV Prevention Programme (NAHIP).
60. In both cases, prevention activities undertaken typically comprise HIV awareness-raising through media campaigns (often using community-specific media), leafleting, advertisements and posters. This work is complemented by direct contact work including workshops, counselling and group activities, in addition to the use of the internet and social marketing tools. In some areas, open-access testing facilities are also available.
61. NAHIP stated that: “The amount currently spent by the Department of Health on HIV prevention is not sufficient.” Its funding of £1 million per annum equates to between £1 and £2 for each African living in England.¹¹⁸ It noted that the £1 million currently spent on prevention for Africans is 0.25% of the £400 million annual cost of treatment and care for the African population. NAHIP concluded by stating that: “Greater spend on prevention is an investment to lower the HIV treatment and care costs to the NHS in the future. Reducing this future burden is one reason why UNAIDS recommends that spending on prevention should be close to 45% of the total spend on treatment and care.”¹¹⁹
62. **We have highlighted the costs of treating HIV, and the long-term savings which could be made through investment in HIV prevention. The current levels of investment in national HIV prevention**

¹¹⁶ See Appendix 8

¹¹⁷ HAUk 19 (Department of Health).

¹¹⁸ HAUk 102.

¹¹⁹ *ibid.*

programmes are insufficient to provide the level of intervention required.

Local HIV programmes

63. In addition to the national campaigns funded by the Department of Health, a range of local provision also exists. Prevention campaigns at the local level are usually funded by Primary Care Trusts, local authorities and charitable donations; typically, providers will draw funding from all of these sources. Some providers, such as Yorkshire MESMAC¹²⁰, match local funding with money received from the national CHAPS programme.
64. Voluntary bodies play a strong role in these local programmes, building on campaigns delivered nationally through more direct work with at-risk groups. 'Outreach'—a diverse term which can include visits to churches, publicising HIV testing in gay nightclubs and promoting condom use in gay saunas—is a particularly important facet of the work of many of these providers.
65. Of these local campaigns, the largest is the Pan-London HIV Prevention Programme (PLHIPP), with a budget of around £3m in 2009/10.¹²¹ For the current financial year, the PLHIPP has experienced a reduction of 20% in the funding received from London PCTs.¹²² This is illustrative of a trend towards disinvestment in local HIV prevention. Sir Nick Partridge, Chief Executive of the Terrence Higgins Trust, suggested that: "Over the past 10 years we have seen a consistent reduction in the investment and funding in local HIV prevention services ... That leaves a gap. It has meant that the responsibility and the expectation on the national programmes are far greater than they can deliver and are currently funded to deliver."¹²³
66. The Minister for Public Health acknowledged the important role of local campaigns and the voluntary sector, stating that: "voluntary sector organisations can be extraordinarily good value for money."¹²⁴ She acknowledged that it was a difficult period for voluntary organisations, but said that "the challenge for funding bodies such as councils, PCTs and others is to look at the provision of services imaginatively"¹²⁵, going on to state that "cuts can be counterproductive because of the costs further down the line. Invest to save."¹²⁶
67. At this point, we pay tribute to the voluntary organisations, without whose efforts the effectiveness of the early response to HIV and AIDS would have been vastly reduced. The Minister praised the "very, very responsible attitude" and "leadership" of the gay community in the early years of the epidemic.¹²⁷ Throughout the inquiry, we have been impressed by the continuing strength of the voluntary sector. At a national level, the AHPN, the National AIDS Trust (NAT)¹²⁸ and the Terrence Higgins Trust have

¹²⁰ A sexual health organisation, based in Yorkshire, that focuses on HIV prevention amongst MSM.

¹²¹ Q 740 (Simon Williams), HAUK 17 (Sima Chaudhury) and personal correspondence with Mark Creelman, Inner North West London PCTs.

¹²² BBC Online, *London HIV services cut as infections rise*, <http://www.bbc.co.uk/news/uk-england-london-13578283>, accessed 15th June 2011.

¹²³ Q 106.

¹²⁴ Q 1125.

¹²⁵ Q 1125.

¹²⁶ Q 1129.

¹²⁷ Q 1089.

¹²⁸ See Appendix 8

coordinated policy and prevention work, whilst groups such as Positively UK¹²⁹, Body and Soul¹³⁰ and National AIDS Manual (NAM)¹³¹ have been firm advocates for patients. Locally, groups such as Yorkshire MESMAC, Leeds Skyline¹³², Summit House¹³³ and the Sussex Beacon¹³⁴ have been integral to local prevention, testing and support strategies. This work must continue to be supported.

68. **Local prevention programmes, and the voluntary sector bodies that deliver them, have played an important role in tackling HIV. Local authorities, health services and other funders should avoid undermining local HIV prevention work when taking budget decisions. The ongoing trend of pressure on local prevention services also underlines the importance of enhanced Government funding for national HIV prevention programmes.**

Wider sexual health campaigns

69. Whilst the Department of Health spends £2.9 million on national HIV prevention work, this is only part of the £10.6 million that the Department spends on sexual health promotion more generally. A range of other campaigns have been supported including, for example, the *Sex: Worth Talking About* campaign, which ran from November 2009 to March 2010. This £6.7 million campaign, which sought to raise awareness of sexual health and promote dialogue around safe sex, ran across various media, including television, radio and newspapers. *It did not mention HIV or AIDS.*
70. The omission of HIV from general sexual health campaigns is a cause for concern. NAT noted that HIV did not feature in the 2006 *Condom: Essential Wear* campaign either. It suggested that HIV awareness should be incorporated into wider sexual health campaigns.¹³⁵ This view was shared by AHPN, which stressed that: “the NHS’ general sexual health campaigns, which are aimed more widely, still need to include information about HIV and increase support to targeted HIV campaigns.”¹³⁶ Positively UK suggested that the lack of general national campaigning on HIV contributed to the stigmatisation of ‘at-risk’ communities.¹³⁷
71. Dr Rowena Merritt, Research Manager at the National Social Marketing Centre¹³⁸, said that campaign financing within the Department of Health took place within “silos”, with HIV sitting separately from wider sexual health, even though different teams of staff were often working to target the same audiences. This, she felt, was “complete madness”.¹³⁹
72. **HIV awareness should be incorporated into wider national sexual health campaigns, both to promote public health and to prevent**

¹²⁹ A policy and advocacy organisation for people living with HIV.

¹³⁰ A charity supporting children, young people and families who are living with or affected by HIV.

¹³¹ See Appendix 8.

¹³² A group providing HIV support services in Leeds.

¹³³ A support service working with people affected by HIV in Dudley and Sandwell.

¹³⁴ A clinical care centre for men and women living with HIV and AIDS.

¹³⁵ HAUK 47.

¹³⁶ HAUK 57.

¹³⁷ HAUK 37.

¹³⁸ A strategic partnership between the Department of Health and Consumer Focus, focusing on social marketing and behaviour change.

¹³⁹ Q 960.

stigmatisation of groups at highest risk of infection. We recommend that there should be a presumption in favour of including HIV prevention in all sexual health campaigns commissioned by the Department of Health.

Do current campaigns work?

73. In the course of visits to HIV clinics in London and Brighton, we received anecdotal evidence which suggested that levels of risky sexual behaviour are on the increase. To an extent, this is borne out by the findings of the 2009 University College London *Gay Men's Sexual Health Survey*. This community-based study found that, of those respondents who were HIV-negative, 46.4% had had unprotected anal sex in the past year; for those who were HIV-positive, this figure rose to 57.7%. In addition, 40.4% of those who were HIV-positive had had unprotected anal sex with a casual (once-only) partner in the preceding year.¹⁴⁰
74. These figures have increased since the mid-1990s as, indeed, has the level of HIV prevalence identified by the study—from 11% of respondents in 1996 to 15.2% in 2008.¹⁴¹ These numbers are alarming, particularly given the high prevalence of HIV amongst the London MSM community.
75. The Department of Health, however, suggested that HIV prevention programmes have been effective according to a number of outcomes for MSM, amongst them:
 - Awareness of the availability of post-exposure prophylaxis (PEP) following potential sexual exposure to HIV increased from 22% before the CHAPS campaign to 56% after the campaign¹⁴²; and
 - Preliminary analysis of data suggested that between 2001 and 2008 there was a fall in numbers of sexual partners among MSM.¹⁴³
76. Likewise, the Terrence Higgins Trust argued that national programmes have demonstrated their effectiveness, suggesting that without them levels of new HIV infection would be much higher. It cited typical target audience recognition rates of 30 to 40% for CHAPS campaigns, as well as a reduction in the number of infections diagnosed amongst MSM between 2007 and 2009.¹⁴⁴
77. Others have suggested that current programmes are failing to either effect behaviour change or stem the tide of new HIV diagnoses. NAM felt that initiatives have been delivered with insufficient energy and pace, with expenditure declining over the past decade.¹⁴⁵ The London Specialised Commissioning Group suggested that national programmes have tended to be output, rather than outcome focused¹⁴⁶, whilst Status argued that a culture of complacency and 'provider knows best' meant that initiatives were failing gay men.¹⁴⁷ The Tuke Institute suggested that campaigns are not

¹⁴⁰ University College London, *Gay Men's Sexual Health Survey 2009*, London 2011.

¹⁴¹ *ibid.*

¹⁴² HAUK 19 (Department of Health).

¹⁴³ *ibid.*

¹⁴⁴ HAUK 64.

¹⁴⁵ HAUK 24.

¹⁴⁶ HAUK 51. The London Specialised Commissioning Group is a coordinated commissioning body for specialised services in London.

¹⁴⁷ HAUK 33. Status is a HIV prevention campaign group.

sufficiently informed by behavioural science, with data on the dynamics of transmission not informing the size or delivery of programmes.¹⁴⁸

78. **We accept that levels of new HIV infection would have been higher without the national prevention programmes, and we support those delivering this work. We feel, however, that more needs to be done to reduce dangerous and risky behaviour that is leading to HIV infection. In part, more funding is needed but, in addition, a broader range of evidence-based approaches are required. We give further detail on this approach in paras 116 to 118.**

Delivering the right prevention campaigns

79. We have described above the existing practice of ‘targeting’ national campaigns at those groups at greatest risk of HIV infection. The balance between targeting and more general campaigns is important. NAM¹⁴⁹, the African Health Forum¹⁵⁰ and AHPN¹⁵¹ argued that targeting is an efficient use of limited resources, given that the epidemic within the UK is largely focused in two particular groups.
80. NAT¹⁵² and the Faculty of Public Health¹⁵³ argued that targeting is sensible, but suggested that high prevalence areas, as well as high prevalence groups, should be targeted. They suggested that broader, more general campaigns should be run alongside community specific activities in areas of high HIV prevalence.
81. FPA¹⁵⁴, HIV Scotland¹⁵⁵ and the Medical Foundation for AIDS and Sexual Health (MedFASH)¹⁵⁶ believed that funding should be given to both universal prevention campaigns and targeted interventions for those most at risk. Awareness of responsibility and risk must extend to the population as a whole; general campaigns may be necessary to educate the wider population. Shield South Yorkshire noted that targeted campaigns at the national level produced materials featuring particular sections of the population, and that these groups were not always present amongst the local population.¹⁵⁷ This made materials difficult to use and prevention messages more difficult to convey.
82. A general HIV prevention campaign, it is felt, would address this. NHS commissioners noted that some people at risk do not identify with campaigns targeted at particular groups.¹⁵⁸ MSM who portrayed themselves as heterosexual to friends and family were one example; young MSM who might not identify as gay were another. These sub-sections of the target groups are therefore missed by targeted campaigns.

¹⁴⁸ HAUk 45. The Tuke Institute is a health think tank and policy organisation.

¹⁴⁹ HAUk 24.

¹⁵⁰ HAUk 81.

¹⁵¹ HAUk 57.

¹⁵² HAUk 47.

¹⁵³ HAUk 38.

¹⁵⁴ HAUk 5 and 83. FPA is a sexual health charity.

¹⁵⁵ HAUk 61. HIV Scotland is the national HIV policy charity for Scotland

¹⁵⁶ HAUk 63 and 66. See also Appendix 8

¹⁵⁷ HAUk 26. Shield is a South Yorkshire-based charity offering support to people living with HIV and/or hepatitis C.

¹⁵⁸ HAUk 9 (LSL Alliance).

83. The 1986 *Don't Die of Ignorance* prevention campaign had a general, national focus. Post-campaign polling showed that 98% of the public understood the transmission routes for HIV.¹⁵⁹ This illustrates what can potentially be achieved through public health campaigns in this area. In contrast, a 2010 survey undertaken by NAT found that 20% of people did not know that HIV was transmitted by sex without a condom between a man and a woman.¹⁶⁰ A recent survey of young people, undertaken by the Sex Education Forum¹⁶¹, found that 27% of respondents had not learnt about transmission routes for HIV.¹⁶²
84. **Both targeted and national HIV prevention campaigns have an important role to play. Given the concentration of HIV infection in two specific groups, we recommend continued targeted HIV prevention campaigning focused on these communities. This should be coordinated at the national level.**
85. **We also recommend that the Department of Health undertake a new national HIV prevention campaign aimed at the general public. This will ensure that HIV prevention messages are accessible to all of the population.**
86. Contributors also considered the technologies used to deliver prevention information. Professor Jonathan Elford, of the Department of Public Health at City University, and Peter Weatherburn both highlighted the increasing role that internet and mobile phone-based applications could play in delivering safe-sex messages.¹⁶³ This is of particular relevance given the increasing role of the internet in generating and forming sexual relationships.
87. Shield South Yorkshire highlighted the reliance upon written and printed materials in current prevention activity.¹⁶⁴ It argued that over-reliance on these forms of delivery failed to take account of the limited literacy and English language skills of some members of the target audience. Television and radio campaigns would lend greater effectiveness—especially when complemented with the group and individual work that we have advocated above.
88. For some audiences, however, printed media remain important. Felton Communications¹⁶⁵ highlighted that the gay press was still the most adept form of targeted media in reaching that audience, but that different messages and different audiences would require different approaches.¹⁶⁶ It was therefore important that campaigns combined all media options.
89. **We recommend that those delivering HIV prevention campaigns, whether nationally or locally, should utilise the full range of available media, including internet, social networking and mobile phone applications. We note that national sexual health campaigns, such as *Sex: Worth Talking About*, have been sufficiently resourced to purchase advertising time with national broadcasters. We**

¹⁵⁹ COI/Gallup poll, March 1987.

¹⁶⁰ HAUK 47.

¹⁶¹ A sex education policy and advocacy group.

¹⁶² Sex Education Forum, *Young people's experiences of HIV and AIDS education*, May 2011.

¹⁶³ Q 910.

¹⁶⁴ HAUK 26.

¹⁶⁵ An advertising agency used by the Terrence Higgins Trust for its media campaigns.

¹⁶⁶ HAUK 84.

recommend that messages around HIV are included in these campaigns in future, ensuring the greatest possible exposure for HIV prevention messages.

Evaluating the effectiveness of campaigns

90. At present, the national HIV prevention programmes commission their own evaluation from within their programme budgets. This is undertaken by Sigma Research, based within the London School of Hygiene and Tropical Medicine. Some contributors, such as Status, questioned the rigour and transparency of these evaluation arrangements, believing that evaluation should be commissioned independently by the Department of Health.¹⁶⁷ In their own submission, Sigma Research also suggested that the evaluation of campaigns would be stronger if commissioned directly by the Department of Health.¹⁶⁸
91. On this point, the Minister for Public Health stated that: "... I am always worried if there is a perception that evaluation is in any way biased, because what really matters is that evaluation is robust and people trust it. Otherwise, 50% of the job of evaluation has failed. So there is obviously, irrespective of the facts, a perception issue that we have to address ..."¹⁶⁹ Whilst we do not question the independence of current evaluation programmes, we agree with the Minister that the perception of independence is of equal importance.
92. At the same time, a large number of witnesses suggested that more resources should be dedicated towards researching the effectiveness of different HIV prevention interventions. These included submissions from the British HIV Association (BHIVA)¹⁷⁰, HIV Scotland¹⁷¹ and Professor Sir Andrew McMichael.¹⁷² Professor Graham Hart, Director of the Division of Population Health at University College London, proposed the establishment of a HIV research strategy committee, to be led by the Department of Health.¹⁷³ He suggested that: "The major health funders in the UK could work together to look at the available evidence of success with regard to prevention, identify the gaps, look at the relationship between biomedical interventions and social and behavioural interventions ... and really determine the direction of travel ... to provide us with a clear strategy for HIV prevention."¹⁷⁴
93. **Whilst we do not doubt the integrity of current evaluation processes, we recommend that the practice of HIV prevention providers commissioning their own evaluation of campaigns be ended. The Department of Health should commission evaluation, ensuring separation from delivery of prevention activity. We also recommend that, once instituted, such independent evaluation activities are used to inform, refine and reinforce subsequent prevention campaigns, providing an evidence-led approach to influencing behaviour.**

¹⁶⁷ HAUk 33.

¹⁶⁸ HAUk 27.

¹⁶⁹ Q 1103.

¹⁷⁰ HAUk 53. See Appendix 8.

¹⁷¹ HAUk 61.

¹⁷² HAUk 14.

¹⁷³ HAUk 8.

¹⁷⁴ Q 897.

94. **Given the significant cost savings that can be accrued from successful HIV prevention work, the Department of Health should prioritise HIV prevention research. We recommend that the Department establish an advisory committee, to give leadership and coordination to biomedical, social and behavioural prevention research.**

Intensive prevention

95. A large majority of our witnesses stressed that there were one set of interventions which had repeatedly proven to be effective. These were intensive group, workshop and one-to-one sessions that supported MSM in modifying sexual risk behaviours. Professor Graham Hart said that: “We have some very good evidence, mainly from the US, that behavioural interventions at the community, group and individual level are highly successful in impacting risk behaviour.”¹⁷⁵ Professor Jonathan Elford went on to say: “Systematic reviews of different behavioural interventions have demonstrated that behavioural interventions can be effective at an individual and community level, but the most successful interventions were intensive. If they were provided at a one-to-one level they would involve, say, 10 one-to-one sessions.”¹⁷⁶
96. Peter Weatherburn highlighted the financial difficulties of delivering this particular type of intervention, reflecting upon the work of the Terrence Higgins Trust: “Unfortunately, it invests in group work that 600 men can attend. Given that there are probably 500,000 to 600,000 homosexually active men in England, that is one in 1,000.”¹⁷⁷ He went on to advocate “... continuing to do the kinds of campaigns that we have done for gay men, for Africans and maybe even for the general population—such as *Condom: Essential Wear*—and following through with a far more robust programme of interventions for those at highest risk.”¹⁷⁸
97. **A range of intensive interventions—including group and individual counselling work—should be delivered for those who are most at risk of either contracting or passing on HIV. This should be set against a backdrop of national campaigns and awareness raising which is properly evaluated and refined for effectiveness.**

Stigma—an obstacle to prevention

What is stigma?

98. During the course of our work, we have heard numerous examples of stigma and discrimination. These include:
- People not wishing to share cups or cutlery with people living with HIV¹⁷⁹;
 - People living with HIV finding themselves homeless and ostracised by their communities¹⁸⁰;
 - Graffiti being sprayed on the homes of people living with HIV¹⁸¹;

¹⁷⁵ Q 882.

¹⁷⁶ Q 884.

¹⁷⁷ Q 883.

¹⁷⁸ Q 903.

¹⁷⁹ Q 541 (Annemarie Byrne, Body and Soul).

¹⁸⁰ HAUK 59 (NAHIP).

- Bullying of the children of people living with HIV¹⁸²;
 - People losing their jobs following disclosure of their HIV status¹⁸³; and
 - Most worryingly, we have heard evidence of stigma being encountered from healthcare professionals, including patients being refused treatment by doctors and dentists.¹⁸⁴
99. HIV stigma is complex, and can take many forms. People living with HIV may experience discrimination, prejudice and stigma from others; they may also begin to internalise these messages and stigmatise themselves. Persistent stigma has effects upon both people living with HIV and upon public health more generally.
100. **Discrimination against those affected by HIV is based, at best, on ignorance and, at worst, on prejudice, and we unreservedly condemn it. This underlines the need for a general public awareness campaign on HIV.**

The causes of stigma

101. There are many deep-seated causes of HIV stigma. Witnesses have suggested that there is a historic association of stigma with diseases or conditions where the person suffering is perceived to be responsible, in some way, for contracting it.¹⁸⁵ There is also, of course, a historic stigma around STIs, reflected in the long-established confidentiality arrangements for GUM services. Progressive and incurable conditions have also historically attracted stigma, as have conditions which are not well understood by the general public.¹⁸⁶
102. Positively UK suggested that people living with HIV may not wish to disclose their status due to a fear that they will be associated with particular behaviour. They fear that they will be judged to have had many sexual encounters, or to have been injecting drug users at some point in the past.¹⁸⁷ Witnesses from religious groups felt that stigma around HIV could be traced back to the 1980s, when it was perceived as a 'homosexual' disease and that "for many faiths it was seen as a judgement".¹⁸⁸

Effects upon public health and prevention

103. Stigma and lack of understanding can undermine HIV prevention efforts. Misinformation circulated about HIV, suggesting that it is a 'judgment' or that it can be cured through non-medical methods, poses a threat to public health messaging. This is especially the case when such statements are made in faith-based settings, given the significant influence of faith leaders in some communities.
104. The potential negative effects of a positive diagnosis (as outlined in para 98) can also have an impact upon prevention. Those at risk from HIV may be deterred from testing and, as a consequence, remain infectious and go on to

¹⁸¹ Q 549 (Annemarie Byrne, Body and Soul).

¹⁸² *ibid.*

¹⁸³ Q 130 (Deborah Jack, NAT).

¹⁸⁴ *ibid.*

¹⁸⁵ Q 550 (Jim Jewers).

¹⁸⁶ *ibid.*

¹⁸⁷ HAUK 37.

¹⁸⁸ Q 647 (Revd Ijeoma Ajibade and Revd Dr Brendan McCarthy).

infect other partners. Difficulties around disclosure of a HIV-positive status can also impact upon adherence to treatment, with negative impacts for the individual and a heightened risk of onward transmission through increased viral load. Stigma, therefore, impacts upon the prevention of HIV.

Legal protections

105. The Equality Act 2010, and the Disability Discrimination Act 2005 before it, have provided a measure of legal protection to people living with HIV. In particular, the Equality Act, in prohibiting the use of pre-employment healthcare questionnaires, removed a significant barrier faced by people living with HIV when accessing employment.¹⁸⁹ It also introduced protection from discrimination for those perceived to be HIV-positive, as well as for people associated with someone who is perceived to have HIV.

What more can be done?

106. In addition to action initiated nationally by Government, we acknowledge the work of others, principally in the voluntary sector, in combating stigma. Commitment to this work needs to be reaffirmed, and such work needs to be supported in a constrained funding environment.

Working with faith leaders

107. Faith and religion play a strong role in the lives of many people. It is essential that faith leaders engage with HIV as an issue and provide effective and truthful support and communication around the subject. We are not convinced that this is happening universally at the moment, although evidence received from faith leaders suggested that opinions and approaches have progressed—to varying extents—over the past 30 years.
108. Much can be learnt from recent work undertaken in the black African community. NAHIP runs a series of initiatives which seek to build and develop the knowledge of faith leaders on HIV. The partnership has produced a toolkit, *Life and Knowledge*, which seeks to support targeted work with faith leaders in this area. The importance of this work has been highlighted by the Department of Health¹⁹⁰, the African Health Forum¹⁹¹ and Dr Sheena McCormack, Clinical Epidemiologist at the MRC Clinical Trials Unit.¹⁹²
109. Reverend Ijeoma Ajibade, of St Philips Earls Court, when reflecting on work with the AHPN, suggested that: “There are myths and taboos around HIV, and what our faith leaders can do in the churches is speak the truth about HIV,” going on to state: “Stigma is very real and one of the things we do in the African Health Policy Network, which is a secular organisation, is give people the tools to speak about HIV, and we then have people who are HIV-positive speaking in churches about HIV, which I personally find very powerful.”¹⁹³ In Leeds, we heard about the complexity of working to raise HIV awareness in a religious community that is often disparate, with many different churches, denominations, languages and cultures.¹⁹⁴

¹⁸⁹ Including HAUk 37 (Positively UK) and HAUk 64 (Terrence Higgins Trust).

¹⁹⁰ HAUk 19.

¹⁹¹ HAUk 81. The African Health Forum is an information platform for health promotion and social care initiatives relevant to African communities in London.

¹⁹² HAUk 56.

¹⁹³ Q 651.

¹⁹⁴ See Appendix 6: Visit to Leeds, 9 May 2011.

110. Work within African communities has been important in developing approaches to religion and HIV. It is not, however, only African churches who need to take on this focus and workload. HIV prevention messages are necessary across all communities and all faiths.
111. **Given the significant influence of faith leaders in some communities, we recommend that the Government, local authorities and health commissioners build upon work already taking place with all faith groups to enlist their support for the effective and truthful communication of HIV prevention messages.**
112. **We recommend that the Department of Health ensures continued funding and support for work, building upon that currently delivered by the African Health Policy Network, which aims to develop the knowledge of faith leaders about HIV. Such work is vital in supporting a wider range of interventions which aim to address, prevent and treat HIV within all communities.**

Peer support groups and the role of people living with HIV

113. HIV-positive people, as advocates and confident service users, can play an important role in addressing stigma through publicising the condition and encouraging dialogue. Francis Kaikumba, Chief Executive of the African Health Policy Network, highlighted the work of its *Ffena* programme, which has trained over 100 people living with HIV to become advocates for understanding of the condition.¹⁹⁵ Silvia Petretti, Community Development Manager at Positively UK, highlighted her work in training 40 women from across Britain to become HIV advocates, undertaking radio interviews and responding to policy issues.¹⁹⁶
114. MedFASH believed that overcoming stigma will require openness, visibility and leadership on the part of people living with HIV.¹⁹⁷ The British Association for Sexual Health and HIV (BASHH)¹⁹⁸ and the Royal College of Physicians suggested that HIV-positive people should be empowered to build their self-confidence in medical settings.¹⁹⁹ Silvia Petretti stated that peer support networks, such as that provided by Positively UK, were vital in equipping people living with HIV to undertake this work.²⁰⁰
115. **People living with HIV need to be empowered to become advocates for understanding of the condition, in order to help to address stigma. We understand the importance of peer support networks and voluntary organisations in supporting this work, and recommend that local authorities and other public sector funders acknowledge the importance of this work in their future funding decisions.**

Combination prevention

116. Over the last 25 years, our knowledge of HIV has increased considerably. Whilst in the 1980s public education was one of the few tools available to prevent transmission, there are now a range of options, encompassing

¹⁹⁵ Q 113.

¹⁹⁶ Q 551.

¹⁹⁷ HAUK 63 and 66.

¹⁹⁸ See Appendix 8.

¹⁹⁹ HAUK 55 and 73.

²⁰⁰ Q 586.

behavioural, social and biomedical interventions, which can limit the spread of the virus. The potential role of treatment as a preventive measure is becoming increasingly prominent. The prevention of mother-to-child vertical transmission, through HIV screening and treatment, has been an important success.

117. These advances mean that public education measures, such as those described above, can now be combined with a range of interventions that either decrease HIV infectivity or limit susceptibility to infection. These measures, integrated with public awareness and engagement of those at high risk, can be brought together to provide 'combination prevention'. We discuss some of the measures that can be incorporated into this combined approach in the following chapters.
118. **Progress achieved over recent decades mean that there are now many facets to HIV prevention. We recommend that the full range of available interventions be used to prevent new HIV infections. We call this approach combination prevention.**

CHAPTER 5: TAKING PREVENTION FURTHER

119. The previous section discussed the importance of HIV publicity and prevention campaigns, supported by more targeted group and individual education for those at highest risk of HIV transmission. We concluded by explaining that these initiatives could be supported by a wider range of measures which, when combined, could provide an effective approach to HIV prevention. Some are already in place, and some need further support. We consider them all here.

Needle exchange

120. HIV is mostly transmitted by sexual contact in the United Kingdom, but that is not the sole method of transmission. As a blood-borne virus, the sharing of injecting drug equipment is a major risk factor for HIV transmission. One way of combating this is to provide needle exchange facilities. Such facilities replace used needles with clean ones, to avoid the need for sharing equipment amongst injecting drug users (IDUs).
121. The Government instituted needle exchange programmes very soon after HIV and AIDS emerged in the United Kingdom. This is widely considered to have been a success.²⁰¹ Professor Mike Kelly, Director of the Centre for Public Health Excellence at the National Institute for Health and Clinical Excellence (NICE), stressed that, “the provision of needles and syringes have been fantastically effective at keeping the HIV epidemic in check in that population”.²⁰² Of the 112,000 HIV diagnoses since the start of the epidemic, only 5% have been as a result of injecting drug use.²⁰³ Just 2.4% of those newly diagnosed with HIV in 2010 acquired their infection through injecting drug use²⁰⁴, and only 2% of those accessing HIV services in 2009 (the latest point for which data is available) were infected through injecting drug use.²⁰⁵ Amongst IDUs as a whole, HIV prevalence was only 1.5% in 2009—though this has risen from a rate of 0.7% in 2000.²⁰⁶
122. These rates compare very favourably to rates in other countries that did not take the same proactive approach to needle exchange programmes. In the United States in 2009, for example, 12% of annual new HIV diagnoses and 19% of those living with HIV overall were infected through injecting drug use.²⁰⁷ Indeed, the HIV epidemic is primarily driven by injecting drug users in many countries in Eastern Europe: in Russia, more than one third of the country’s IDUs are living with HIV; whilst in the Ukraine, prevalence amongst IDUs is between 39% and 50%.²⁰⁸

²⁰¹ See, for example, HAUK 54 (Royal College of GPs), HAUK 63 (MedFASH), HAUK 59 (NAHIP), Q 873 (Professor Noel Gill).

²⁰² Q 337.

²⁰³ HAUK 59 (NAHIP).

²⁰⁴ Health Protection Agency, United Kingdom: New HIV diagnoses data to end of December 2010, *op. cit.* (Calculation based on 160 diagnoses out of an estimated 6,750 cases = 2.37%).

²⁰⁵ Health Protection Agency, *HIV in the United Kingdom (2010 Report)*, *op. cit.*

²⁰⁶ Health Protection Agency, *Shooting Up: Infections among injecting drug users in the UK 2009*, November 2010.

²⁰⁷ Centers for Disease Control and Prevention, *HIV in the United States*, July 2010.

²⁰⁸ UNAIDS, *UNAIDS Report on the Global AIDS Epidemic 2010*, p73: http://www.unaids.org/globalreport/global_report.htm

123. However, in light of the rise in prevalence in this country over the past decade, and the geographical variation in prevalence—which ranges from 0.6% in Scotland to 4.1% in London²⁰⁹—we must not be complacent.²¹⁰ One potential threat in this respect is the perception that needle exchange facilities could lead to an increase in criminality. This argument was emphatically refuted by Dr Ewen Stewart, Chair of the Royal College of General Practitioners' (RCGP) Sex, Drugs and HIV Group, who said that, “the evidence is actually to the opposite: that by bringing people into treatment, you reduce criminality; you reduce their need to fund a drug habit through criminal activity and therefore it has a wider social benefit than just a benefit to the individual.”²¹¹ Professor Graham Hart added that there was “no evidence” of increased drug use resulting from needle exchange”.²¹²
124. Needle exchange programmes are a crucial component of a successful response to a blood-borne virus such as HIV. Statistics show continuing low levels of HIV incidence amongst injecting drug users. We are therefore pleased to see that the Minister for Public Health made clear that, “At the moment there are certainly no plans to get rid of needle exchanges.”²¹³ We would go further. Given the problems elsewhere, we call on the Government to encourage other countries to heed the lessons learned in the United Kingdom, in order to combat HIV amongst injecting drug users worldwide.
125. **We support the continued provision of needle exchange programmes. The Government should use their influence, both through partnerships such as UNAIDS and their bilateral relationships, to make clear the benefits of needle exchange facilities, and encourage countries whose epidemics are driven by injecting drug use to institute or expand such programmes.**

Education in schools

126. Education is a critical part of HIV and AIDS prevention work. One of the most important targets for such education must be children and young people. HIV case reports show that one in ten new HIV diagnoses in the UK are amongst people aged between 15 and 24 years old, and incidence estimates suggest that one in six of those newly infected with HIV are young people.²¹⁴ Communicating the importance of safe sexual behaviour and the need to take care of oneself in relationships, therefore, is vital. Within schools, this is traditionally done in the subject of sex and relationships education (SRE). The Government has committed to a review of Personal, Social, Health and Economic education (PSHE), of which SRE forms part, although the remit has not yet been decided.²¹⁵
127. SRE is a broad term, which applies to learning about the “emotional, social and physical aspects of growing up, relationships, sex, human sexuality and sexual health”.²¹⁶ Its main aim is not to teach children about sex; it is about ensuring their safety and security in intimate relationships. These are key

²⁰⁹ Health Protection Agency, *Shooting Up: Infections among injecting drug users in the UK 2009*, op. cit.

²¹⁰ HAUk 63 (MedFASH).

²¹¹ Q 675.

²¹² Q 888.

²¹³ Q 1121.

²¹⁴ HAUk 68 (Health Protection Agency).

²¹⁵ Q 1013 (Nick Gibb MP).

²¹⁶ FPA, Sex and relationships education factsheet, January 2011.

skills to have throughout life, and issues that Nick Gibb MP, Minister of State for Schools, stressed were “very, very important to this Government”.²¹⁷

128. Teaching requirements in relation to SRE, HIV and AIDS are complicated. The Sex Education Forum has detailed the position, which is outlined in Box 1. In summary, learning about HIV, AIDS and other STIs are the only aspects of sex education that are compulsory for all maintained secondary schools.²¹⁸ Present teaching looks at HIV and AIDS within the science curriculum. However, the separate subject of SRE, with its focus on broader social issues (which can increase levels of safe sexual behaviour²¹⁹), should also be considered as part of HIV and AIDS prevention efforts.

BOX 1

Existing requirements around sex and relationships education²²⁰

- (1) It is compulsory for all maintained schools to teach some parts of sex education, that is the biological aspects of puberty, reproduction and the spread of viruses. These topics are statutory parts of the National Curriculum Science which must be taught to all pupils of primary and secondary age.
- (2) There is also a requirement for secondary schools to teach about HIV, AIDS and sexually transmitted infections as part of the National Curriculum Science.
- (3) The broader topic of SRE is currently not compulsory but is contained within non-statutory PSHE within the National Curriculum and is strongly recommended within Government SRE Guidance (2000). School governors are in law expected to give ‘due regard’ to this guidance.
- (4) Both primary and secondary schools are legally obliged to have an up-to-date SRE policy that describes the content and organisation of SRE taught outside the Science Curriculum. In primary schools a decision not to teach SRE outside the Science Curriculum should also be documented in the policy.
- (5) It is the responsibility of the school’s governing body to ensure that the policy is developed and is made available to parents. Parents have a right to withdraw their children (until the age of 19) from any school SRE taught outside the Science Curriculum.
- (6) To qualify for Healthy School status, there must be a planned programme of PSHE which includes SRE in place.²²¹
- (7) Schools have a legal duty to ensure the wellbeing of their pupils and SRE contributes to this duty.

Standards of teaching

129. Even though teaching about HIV and AIDS is part of the National Curriculum, it is inadequate at present. A survey of 821 young people

²¹⁷ Q 1056.

²¹⁸ Education (Non-Maintained Special Schools) (England) Regulations 1999. (SI no 2257).

²¹⁹ HAUK 49 (Sex Education Forum).

²²⁰ Sex Education Forum, *Current status of Sex and Relationships Education*, March 2011.

²²¹ Healthy Schools Status is a Department for Education and Department of Health accreditation scheme.

conducted by the Sex Education Forum this year found that a quarter of young people had not learnt about HIV and AIDS in school; a problem that was more pronounced amongst older children.²²² This echoed the findings of a 2007 Ofsted report, which stated that HIV and AIDS received insufficient emphasis within schools.²²³

130. The content of HIV and AIDS teaching is also a problem. The Sex Education Forum survey found that children were most likely to have learnt about the transmission of HIV (73%), but that learning about stigma and attitudes was less common (41%).²²⁴ Body and Soul felt that the balance of information failed to properly communicate the risks of acquiring HIV.²²⁵
131. Many of the concerns about HIV and AIDS teaching were expressed about SRE more broadly. A 2008 Sex Education Forum survey found that 92% of young people learned about biological aspects of sex, but only 21% were taught about relationship skills.²²⁶ The need for a broader curriculum was widely supported.²²⁷ Dissatisfaction was shared by teachers and school leaders.²²⁸

Improving the system

132. One area for possible development relates to mandatory teaching of SRE in schools. Lucy Emmerson, Principal Officer of the Sex Education Forum, argued that mandatory teaching would be a “huge lever” to help ensure that everyone had an entitlement to learning about SRE.²²⁹ This call was supported elsewhere.²³⁰ However, the Minister for Schools outlined that statutory provision was “not the approach we are taking to education policy”²³¹, and that it was “imperative that parents will maintain a right to withdraw their children from SRE lessons”.²³²
133. The age at which teaching begins is important too. Currently, teaching about HIV and AIDS begins in secondary school, whilst very basic biological information is first delivered to children aged between four and seven years old (at Key Stage 1). Existing guidance calls for teaching on SRE around healthy lifestyles and relationships to begin at the same age.²³³ This had support from teachers, parents and governors²³⁴ and from sexual health organisations.²³⁵ Those calling for such provision stressed, though, that material had to be age-appropriate. This means that, at the earliest stage,

²²² Sex Education Forum, *Young people's experiences of HIV and AIDS education*, May 2011.

²²³ Ofsted *Time for Change? Personal, social and health education*, London 2007.

²²⁴ Sex Education Forum, *Young people's experiences of HIV and AIDS education*, *op. cit.*

²²⁵ HAUK 22.

²²⁶ HAUK 49 (Sex Education Forum).

²²⁷ See, for example, Q 593 (Sarah Smart, PSHE Association), Q 664 (Professor David Albert Jones, Anscombe Bioethics Centre, Catholic Church), HAUK 46 (Brook).

²²⁸ Durex, *Survey of parents, teachers and governors on Sex and Relationships Education in England (Executive Summary)*, London 2011.

²²⁹ Q 616.

²³⁰ Q 617 (Simon Blake, Brook), Q 116 (Sir Nick Partridge), HAUK 22 (Body and Soul).

²³¹ Q 1052.

²³² Q 1057.

²³³ Sex Education Forum, *Current status of Sex and Relationships Education*, *op. cit.*

²³⁴ Durex, *Survey of parents, teachers and governors on Sex and Relationships Education in England (Executive Summary)* *op. cit.*

²³⁵ HAUK 5 (FPA), Q 627 (Sarah Smart).

teaching is about supporting children to be safe, and providing what Lucy Emmerson called “the building blocks and the language to build on”.²³⁶

134. Teachers must be properly trained for this teaching. A survey of parents, teachers and governors indicated that more training was the number one priority for teachers in improving SRE, with 80% of school leaders feeling insufficiently trained and confident about the topic.²³⁷ The Minister for Schools stressed that the PSHE review would consider training requirements for teachers.²³⁸

Conclusion

135. Broad teaching about sex, relationships and HIV can deliver key HIV prevention messages. It is an area acknowledged by the Government to be important, and one where the need to improve has also been taken on board.²³⁹ This commitment to bring influence to bear will work to improve standards.
136. Although the Minister for Schools stressed that he did not wish to pre-empt the findings of the PSHE review, it is clear that mandatory teaching of SRE is an unlikely development. The Minister’s position was that change could be encouraged in other ways, such as through regard for SRE guidance in academy funding agreements.²⁴⁰ We are of the view, however, that a statutory basis for SRE is essential. This would ensure that SRE is given appropriate priority in school timetables, driving the development of consistent standards. It would also support the integration of HIV and AIDS teaching into SRE, avoiding reliance on the science curriculum to provide all teaching on what is a wide and complex subject.
137. Teaching should begin as early as possible. There is no question at all of this being explicit, or encouraging of sexual behaviour. At the earliest stages, teachers would simply deliver messages about the importance of being protected against abuse and pressure. In 2009, nearly 5% of children aged between 11 and 17 years old reported being sexually abused by an adult or another young person²⁴¹; and one in four 18 to 24 year olds reported being physically attacked, sexually abused or severely neglected during their childhood.²⁴² Early, effective teaching could help to keep children safe from an early age. This could then be built on in order to develop the knowledge and skills required to prevent the acquisition and spread of HIV and AIDS.
138. Although external providers can be “memorable”²⁴³, this teaching should be delivered by trained and confident teachers, to ensure as many young people as possible gain the skills they need.²⁴⁴ Existing training requirements, which only expect familiarity with National Curriculum guidance²⁴⁵, are simply insufficient.²⁴⁶

²³⁶ Q 631.

²³⁷ Durex, *Survey of parents, teachers and governors on Sex and Relationships Education in England (Executive Summary)*, *op. cit.*

²³⁸ Q 1035.

²³⁹ Q 1132 (Anne Milton MP).

²⁴⁰ Q 1057.

²⁴¹ NSPCC, *Child cruelty in the UK 2011: An NSPCC study into childhood abuse and neglect over the past 30 years*, February 2011.

²⁴² *ibid.*

²⁴³ Q 602 (Simon Blake).

²⁴⁴ Q 603 (Sarah Smart), Q 598 (Simon Blake).

²⁴⁵ Q 597 (Sarah Smart). This requirement is QTS 15:

<http://www.tda.gov.uk/trainee-teacher/qts-standards/knowledge-and-understanding/subjects-curriculum/Q15.aspx>

²⁴⁶ HAUK 64 (Terrence Higgins Trust).

139. Ensuring that as many young people as possible can access good quality SRE is crucial. We recommend that the Government's internal review of PSHE considers the issue of access to SRE as a central theme. Teaching on the biological and social aspects of HIV and AIDS should be integrated into SRE.
140. Whilst acknowledging that the review is yet to complete its work, we recommend that the provision of SRE should be a mandatory requirement within the National Curriculum, to enable access for all. Such education should begin within all schools from Key Stage 1, though this teaching must be age-appropriate.
141. There is an important role to be played by external providers, but we recommend that SRE should be primarily delivered by teachers, who must be trained to deliver this teaching. This training must focus on all aspects of HIV and AIDS, to ensure that teachers are confident on the subject.

Preventing mother-to-child transmission

142. During the course of our Committee visits, we received evidence of the effectiveness of current practice in limiting the transmission of HIV from mothers who are infected to their children. Measures taken, including HIV screening, reduction of viral load in pregnant women (through antiretroviral therapy), the provision of free formula milk²⁴⁷ and sperm washing²⁴⁸, have proven highly successful in limiting transmission to children.²⁴⁹
143. Evidence suggests that, without intervention, around 30% of children born to HIV-positive mothers would be infected with the virus.²⁵⁰ At the Chelsea and Westminster Hospital, with appropriate interventions, the rate of transmission was under 1%, with only two cases in seven years, from over 250 deliveries.²⁵¹ The national rate stands at around 3%; between 2002 and 2008, just over 210 HIV-positive children were born from a total of more than 7,500 deliveries by HIV-positive mothers.²⁵² The multidisciplinary work of the HIV family clinic at Chelsea and Westminster, including psychological support, was likely to have been a significant factor in securing a better than average rate there.
144. Written evidence from the Children's HIV Association (CHIVA) suggested that free infant formula milk, vital in preventing infection via breast-feeding, is not always provided to mothers who have no recourse to public funds.²⁵³ In the main, this problem affects individuals with an irregular immigration status. Provision—coordinated through local authorities—is variable across the country, producing a 'postcode lottery'. CHIVA argued that there is both an individual and a public health benefit in ensuring that local authorities provide free infant formula milk to HIV-positive mothers who have no recourse to public funds. We support this view. The costs of providing this

²⁴⁷ This is because HIV can be transmitted through breast-feeding; the provision of free infant formula milk ensures that HIV positive mothers can avoid passing on the virus in this way.

²⁴⁸ This is a procedure to remove the HIV virus from semen prior to artificial insemination, for the avoidance of transmission to both mother and child.

²⁴⁹ See Appendix 5: Visit to London Clinics, 31 March 2011.

²⁵⁰ HAUK 10 (Children's HIV Association)..

²⁵¹ See Appendix 5, *op cit*.

²⁵² Health Protection Agency, New HIV diagnoses data to end of December 2010, *op. cit.*.

²⁵³ HAUK 10.

service are minute compared with the costs, both financial and emotional, of a lifetime of treatment for HIV infection.

145. The provision of universal opt-out testing in antenatal clinics has been a very important achievement. Introduced in 2000, this measure has seen testing acceptance rates of 95% amongst pregnant women attending clinics, ensuring that almost all pregnant women are screened for HIV.²⁵⁴ A diagnosis can then be followed by the measures outlined above to prevent mother-to-child transmission, as well as partner notification and other follow-up work. This makes the diagnosis itself an important measure in preventing onward transmission. Antenatal testing has been hailed as “the most successful HIV testing achievement.”²⁵⁵ This success illustrates the potential of wider availability of testing, and supports arguments made in our later discussion of testing arrangements (see para 179).
146. **Procedures developed to limit the transmission of HIV from mother-to-child have been an outstanding success. We recommend that the Department of Health and commissioners ensure that such services continue to be provided as required. For the same reason, we also recommend that local authorities provide free infant formula milk to HIV-positive mothers who have no recourse to public funds.**

Treatment as prevention

147. A number of submissions have referred to the value of earlier diagnosis and treatment in HIV prevention efforts (see paras 174 to 175). Such claims are made on the basis of evidence which suggests that the behaviour of those infected changes following a HIV diagnosis; and on research which indicates that infectivity is reduced when on antiretroviral treatment, through the reduction of viral load. In addition, there is growing evidence that early commencement of treatment has benefits for those infected with HIV, preventing damage to the immune system which might otherwise take place. There is, therefore, a growing body of evidence which suggests that there are both individual and public health benefits to be gained from early treatment.
148. Results of a ‘treatment as prevention’ trial were published by the US National Institutes of Health in May this year. This research (which took place at 13 international sites, although none were in the UK) suggested that, if an HIV-positive person adheres to an effective antiretroviral treatment regimen, the risk of transmitting the virus to an uninfected sexual partner can be reduced by 96%.²⁵⁶ This work may begin to make the case for commencing antiretroviral therapy at an earlier stage than currently recommended. Indeed, written evidence from Professor Jonathan Weber called for scrutiny of existing treatment guidelines to explore whether treatment should be provided earlier for preventive effect.²⁵⁷
149. Behavioural change as a result of HIV treatment and associated interventions has a broader link to early testing and diagnosis, which is discussed in detail in the next chapter. Ruth Lowbury, Chief Executive of MedFASH, cited US research which showed that the likelihood of unprotected sex was 68% lower

²⁵⁴ HPA, *HIV in the United Kingdom (2010 Report)*, *op. cit.*

²⁵⁵ Q 244 (Dr Keith Radcliffe).

²⁵⁶ Cohen MD *et al.*, *Prevention of HIV-1 Infection with Early Antiretroviral Therapy*, New England Journal of Medicine, July 2011.

²⁵⁷ HAUK 71.

when people were aware of their own HIV-positive status.²⁵⁸ Links between diagnosis, treatment and positive behaviour change were also acknowledged by Professor Mike Kelly of NICE.²⁵⁹

150. **Treatment has an increasingly important role to play in preventing HIV infection. We note research demonstrating the potential for earlier antiretroviral treatment as a preventive measure. We recommend that the Department of Health, National Institute for Health Research²⁶⁰, Medical Research Council and other research funders provide support in order to examine the utility of such approaches in the United Kingdom. In addition, the Department of Health should keep policy in this area under review as further research continues to emerge.**
151. In addition to the earlier commencement of treatment, recent research has highlighted the potential role of antiretroviral pre-exposure prophylaxis (PrEP) measures—such as microbicidal gel and oral tablets for those at high risk of infection—in reducing transmission.²⁶¹ This was referenced in a number of evidence submissions.²⁶² However, most asserted that more United Kingdom-based evidence is required before wider roll-out. In oral evidence, though, Dr Sheena McCormack detailed difficulties in obtaining funding for research into developing the effectiveness of microbicidal measures.²⁶³ BHIVA and BASHH, together with other stakeholders, are currently drawing up a position statement with regard to the use of PrEP in the United Kingdom.
152. Another prevention measure, post-exposure prophylaxis (PEP), is already available in the UK through GUM clinics. With PEP, individuals who have had a potential exposure to HIV can take a course of antiretrovirals for one month afterwards to limit the chances of infection. This measure has also been used to protect healthcare workers who have had a possible workplace exposure to HIV.
153. Several contributors to the inquiry, including the African Health Forum²⁶⁴, stressed the need for easier access to PEP to ensure take-up. NAHIP highlighted that commissioning routes for ‘treatment as prevention’ could become complicated under the proposed NHS reforms, given that those two aspects of HIV services will be divided under the new system.²⁶⁵
154. There are, however, concerns that too flexible an approach to the distribution of PEP may encourage the development of viral resistance; there is also a feeling that supply should continue to be managed by GUM clinics, allowing supportive counselling and behaviour change work to be delivered at the same time.²⁶⁶ Furthermore, an approach that is too flexible may

²⁵⁸ Q 237.

²⁵⁹ Q 331.

²⁶⁰ An NHS-led research institute, which commissions and funds research.

²⁶¹ Including, for example, Partners PrEP Study, University of Washington International Clinical Research Centre, July 2011. See http://depts.washington.edu/uwicrc/research/studies/files/PrEP_FAQ.pdf

²⁶² Including HAUk 56 (Dr Sheena McCormack).

²⁶³ QQ 458–461.

²⁶⁴ HAUk 81.

²⁶⁵ HAUk 59.

²⁶⁶ Q 515 (Dr Simon Barton).

encourage PEP to be seen as an easy 'solution' to HIV, and dilute messages encouraging use of prevention measures such as condoms.

155. **We recommend that the Department of Health, National Institute for Health Research, Medical Research Council and other research funders support programmes of work which examine the utility of pre-exposure prophylaxis. This research should take place both in the United Kingdom and in international settings. We recommend that the availability of post-exposure prophylaxis should continue to be determined by clinicians within GUM clinics.**

Dealing with HIV in prisons

156. The prison system is an environment of real risk for acquiring HIV. Nearly 200,000 prisoners pass through the system every year, and those with alcohol and drug dependencies, such as injecting drug users, are disproportionately represented.²⁶⁷ If we are serious about giving HIV prevention the priority it deserves, tackling HIV in prison cannot be ignored.
157. However, data in this area is seriously inadequate. Surveillance systems were only able to separate out diagnoses made in prisons for the first time in January 2011.²⁶⁸ Figures that are available are likely to underestimate seriously the number of people living with HIV in prison.²⁶⁹
158. Whilst there is no official figure for prevalence, HPA figures for England²⁷⁰ would suggest that diagnosed HIV prevalence was at nearly 2.2 people per 1,000 of prison population at the end of 2009.²⁷¹ Even with the likely underestimation, this would still be more than 50% higher than the estimated prevalence (of people both diagnosed and undiagnosed) of 1.4 people per 1,000 across the United Kingdom as a whole in that year.²⁷²
159. Within prisons, services are the responsibility of Offender Health, a joint Department of Health and National Offender Management Service unit, and are commissioned by Primary Care Trusts.²⁷³ Under proposals for reform, integrated prison health services are to be commissioned at a national level by the NHS Commissioning Board.²⁷⁴

Testing in prisons

160. The need to increase the uptake of testing is of particular importance in prisons given the relatively high prevalence of HIV.²⁷⁵ Offender Health

²⁶⁷ Health Protection Agency and Department of Health, *Health protection in prisons, 2009–2010 report*, March 2011.

²⁶⁸ HAUK 92 (Offender Health).

²⁶⁹ Health Protection Agency and Department of Health, *Health Protection in prisons, 2009–10 Report*, *op. cit.*.

²⁷⁰ 182 people living with HIV in prison in England in 2009. See HAUK 89 (International Centre for Prison Studies).

²⁷¹ Calculation based on the 2009 HPA estimate of 182 people living with HIV in prison in England, and December 2009 prison population data for England and Wales (84,231 total inmates). Calculation was therefore: $(182/84231) \times 1000 = 2.161$ per 1,000. Prison population figures taken from HM Prison Service population data:
http://www.hmprisonservice.gov.uk/assets/documents/100049D8population_bulletin_monthly_december_2009.pdf

²⁷² Health Protection Agency, *HIV in the United Kingdom (2010 Report)*, *op. cit.*

²⁷³ HAUK 92 (Offender Health).

²⁷⁴ Department of Health, *Healthy Lives, Healthy People: consultation on the funding and commissioning routes for public health*, November 2010, para 3.30. See also Q 225 (Dr Gabriel Scally).

²⁷⁵ HAUK 89 (International Centre for Prison Studies), HAUK 22 (Body and Soul), Q 258 (Ruth Lowbury).

stressed that it had worked with commissioners and providers to allow more opportunities for HIV testing. Levels of service provision have not, though, been mapped across the country. A review against prison quality indicators, which include access to sexual health services such as testing, is being conducted by NHS South West and may tell us more.²⁷⁶

161. We do know, however, that testing is not offered and recommended on a routine basis for those entering prison. Staff we heard from at HMP Brixton were not opposed to such a development on an opt-out basis (this is where a test is offered and then carried out, unless the person specifically objects).²⁷⁷ However, staff mentioned the need to bear in mind the stresses upon those entering prison for the first time.²⁷⁸

Treatment for prisoners with HIV

162. Treatment for those with HIV is important both in terms of their individual health, and in terms of reducing their infectivity (see paras 174 to 175). Standards of care for all health services in prisons are supposed to be equivalent to those provided in the community.²⁷⁹ HPA figures indicated that, in 2008, the proportion of prisoners treated with antiretroviral drugs is similar to those diagnosed outside prison in England.²⁸⁰ However, standards vary across the country.²⁸¹ Silvia Petretti of Positively UK asserted that she had seen “a number of women who have been delayed or denied treatment in our prisons in the UK, and this is jeopardising their lives.”²⁸²
163. There is no doubt, though, that providing continuing care for those with HIV in a fast-changing prison system is a challenge. Dr T Moss and A Woodland, noted the potential for interruption of antiretroviral therapy.²⁸³ Offender Health stressed that it had worked with the British HIV Association to better understand the challenges in relation to HIV-positive prisoners, and developed an integrated computer system to share information nationally.²⁸⁴

Prevention in prisons

164. Prevention covers a number of areas. One is education. Offender Health made reference to a number of health promotion initiatives, including DVDs, posters and leaflets, but we did not receive any evidence as to how widely these were available. Providing condoms, lubricant and dental dams is another element of preventive work. Although the application process—where condoms are requested from a healthcare worker—is “as per all other requests for healthcare in prisons”²⁸⁵, Silvia Petretti felt that it disincentivised their use, as “that is like outing yourself as having gay sex in prison, which people will not do.”²⁸⁶

²⁷⁶ HAUK 92 (Offender Health).

²⁷⁷ See Appendix 8.

²⁷⁸ Appendix 7: Visit to HMP Brixton, 17 June 2011.

²⁷⁹ HAUK 92 (Offender Health).

²⁸⁰ Health Protection Agency *Health protection in prisons, 2009–2010 report*, op. cit.

²⁸¹ See, for example, Q 102 (Deborah Jack).

²⁸² Q 554.

²⁸³ HAUK 25. Both were former healthcare workers.

²⁸⁴ HAUK 92.

²⁸⁵ *ibid.*

²⁸⁶ Q 558.

Conclusion

165. The present approach to HIV and AIDS in prisons is not good enough. Data needs to be more robust, and the availability of sexual health services across the country should be mapped. The performance review underway through NHS South West is welcome, but a specific review relating to HIV and AIDS is also required.
166. Establishing the scale of the challenge must then be the basis for action. Ensuring effective care, equivalent to that in the community, must be the goal. Professor Mike Kelly of NICE indicated that offender health, “might be an area that NICE could conceivably take forward in the future”.²⁸⁷ Given the persuasive and high-quality nature of such guidelines elsewhere (see paras 241 to 248), this would be constructive.
167. Prisoners should be offered opt-out HIV tests on a routine basis upon entering the prison system. They should also have confidential access to condoms, lubricant and dental dams. We have proposed that routine opt-out testing be put in place for those registering with a new GP (see para 192); this should be no different for prisoners. This is especially so when prevalence within prison is likely to be greater than 2 per 1,000, the threshold at which such testing is recommended elsewhere.
168. The shift to central commissioning of offender health services provides a real opportunity across all of these areas; commissioning for the whole prison estate can ensure consistency and equity for the good of the prison population as a whole.²⁸⁸ In the meantime, the Government needs to make clear to prison governors what is required of them, to best serve individual and public health needs across the prison estate.
169. **We recommend that the Government pursue its plans to commission offender health services centrally, which would lead to better equity and continuity of care for prisoners.**
170. **Data on HIV in prisons must be improved. The Health Protection Agency should utilise surveillance data newly available to provide a robust estimate of the prevalence and profile of HIV within the prison population. At the same time, a review exercise into offender health services in public prisons is underway. The Government should supplement this with a review of the extent and nature of HIV prevention, testing and treatment services within public prisons, to determine the levels of provision across the country.**
171. **We recommend that best practice for managing HIV in prisons is made clearer. The Government should commission NICE to produce guidance for the management of offender health, which should include specific protocols for HIV prevention, testing and treatment.**
172. **In the meantime, the Government should draw up a guidance note to prison governors to outline best practice for managing HIV in prisons. This must stress the need for high-quality, continuous treatment and care; robust testing policies, including routine opt-out testing on entry into prison; and the provision of condoms in a confidential manner. Governors should implement these policies within their prisons as soon as possible.**

²⁸⁷ Q 334.

²⁸⁸ Q 102 (Deborah Jack), Q 307 (Ruth Lowbury).

CHAPTER 6: 'DON'T DIE OF IGNORANCE'

173. One of the most important messages of the early response to HIV and AIDS was encapsulated in the slogan on the front of leaflets sent to every home in the United Kingdom: "Don't die of ignorance". Swift death need no longer be the outcome of contracting HIV, but the truth remains that too many people are still ignorant of their status. This is in spite of the fact that testing has clear individual and public health benefits.
174. For the individual, diagnosis brings with it access to HIV treatment and the benefits of antiretroviral therapy and specialist care. The earlier the diagnosis, the better the outlook. Dr Valerie Delpech of the HPA said that a very late diagnosis meant a "10-times-higher chance of dying within the first year"²⁸⁹, and an estimated life expectancy 10 years lower than for those receiving timely treatment.²⁹⁰
175. In terms of public health, HIV testing plays an important preventive role, which must be considered alongside other interventions discussed in previous chapters. As Dr Paul Cosford, Interim Executive Director of Health Protection Services at the HPA, outlined, "Detecting early and treating early reduces the pool of people who are available to provide onward transmission".²⁹¹ One study found that being diagnosed and treated reduced the transmission risk amongst heterosexual couples by as much as 96%.²⁹² A positive diagnosis can also reduce levels of risk behaviour²⁹³, and allows for tracing of previous sexual partners to find others potentially infected. Even if negative, a HIV test provides an opportunity for one-to-one education on risk reduction.
176. In spite of these clear benefits, it is estimated that more than a quarter of those living with HIV in the United Kingdom have not been diagnosed (see para 16), whilst there has been no decrease in the undiagnosed prevalence of HIV in the past decade.²⁹⁴ Diagnosis, when it comes, is often late: in 2009 52% of diagnoses were late²⁹⁵, with 30% 'very late'²⁹⁶—proportions which were higher amongst heterosexual men and women²⁹⁷ and black African populations.²⁹⁸ Even worse, opportunities to diagnose patients earlier are being missed. A significant proportion of people diagnosed late had been seen by healthcare professionals in the preceding year with symptoms which were likely to be related to HIV.²⁹⁹
177. Increasing the levels of testing and prompt diagnosis must, therefore, be a major priority in the fight against HIV and AIDS.³⁰⁰ Professor Noel Gill of the HPA felt that increasing levels of testing was the number one policy priority³⁰¹; Dr Gabriel Scally, Regional Director for Public Health (South West) at the

²⁸⁹ Q 32.

²⁹⁰ HAUK 53 (British HIV Association).

²⁹¹ Q 863.

²⁹² Cohen MD *et al.*, *Prevention of HIV-1 infection with Early Antiretroviral Therapy*, New England Journal of Medicine, July 2011.

²⁹³ Q 331 (Professor Mike Kelly), Q 237 (Ruth Lowbury), HAUK 50 (Halve It Coalition).

²⁹⁴ HAUK 97 (Health Protection Agency).

²⁹⁵ Health Protection Agency, *HIV in the United Kingdom (2010 Report)*, *op.cit.*

²⁹⁶ *ibid.*

²⁹⁷ *Ibid.*

²⁹⁸ HAUK 59 (NAHIP).

²⁹⁹ HAUK 53 (British HIV Association), HAUK 64 (Terrence Higgins Trust), HAUK 19 (Department of Health).

³⁰⁰ Q 233 (Dr Keith Radcliffe), Q 870 (Dr Paul Cosford).

³⁰¹ Q 861.

Department of Health, called early diagnosis “absolutely crucial”.³⁰² The Minister for Public Health stressed that “more needs to be done to reduce undiagnosed HIV and particularly the late diagnosis of HIV”.³⁰³

How testing works

178. At present, around 80% of HIV tests are conducted within genitourinary medicine (GUM) clinics.³⁰⁴ The proportion of those attending GUM services who were tested for HIV increased from 51% in 2001 to 77% in 2008 and 2009.³⁰⁵ Amongst MSM, testing uptake in GUM services is at nearly 90%.³⁰⁶
179. HIV testing guidelines recommend that such testing is done on a routine ‘opt-out’ basis.³⁰⁷ This means that patients are offered and recommended a test, which is then carried out unless the patient decides against it. This was built on work done within antenatal clinics, where since 2000 it has been the norm, with testing uptake amongst pregnant women at 95%.³⁰⁸ The success of this policy was widely acknowledged.³⁰⁹ AHPN felt that uptake rates in the antenatal setting “provided good evidence ... that normalising HIV testing through the adoption of an opt-out approach to testing can dramatically increase uptake.”³¹⁰ Dr Keith Radcliffe, Chair of BASHH and Chair of the Joint Specialty Committee in Genitourinary Medicine at the Royal College of Physicians, contrasted this shift in culture with the previous approach of identifying those felt to be at-risk, which was “problematic” because it “singled out” individuals.³¹¹
180. Opt-out testing is to be distinguished from mandatory testing, where the case has not been established. Dr Ian Williams, the then Chair of BHIVA, felt such testing contravened the “general ethos of how clinicians work in terms of care of patients”.³¹² Deborah Jack, Chief Executive of NAT, was opposed on ethical grounds³¹³, whilst Dr Keith Radcliffe felt that it would drive people underground.³¹⁴

HIV testing—the way forward

181. Testing needs to move beyond the antenatal and GUM settings. At the same time, the experience of routine opt-out testing in both settings shows that it can provide a “normalised” culture for testing and diagnosis in clinical practice, which can reduce stigma around HIV³¹⁵ and boost testing rates.³¹⁶ This should be the guide to expansion.³¹⁷

³⁰² Q 180.

³⁰³ Q 1089.

³⁰⁴ HAUK 53 (British HIV Association).

³⁰⁵ Health Protection Agency, *HIV in the United Kingdom (2010 Report)*, *op. cit.*

³⁰⁶ Health Protection Agency, *HIV in the United Kingdom (2010 Report)* slide set, *op. cit.*

³⁰⁷ British HIV Association, British Association for Sexual Health and HIV, British Infection Society, *UK National Guidelines for HIV Testing 2008, September 2008*.

³⁰⁸ Health Protection Agency, *HIV in the United Kingdom (2010 Report)*, *op. cit.*

³⁰⁹ Q 30 (Dr Valerie Delpech), Q 244 (Dr Keith Radcliffe), HAUK 9 (LSL Alliance), HAUK 47 (National AIDS Trust), HAUK 64 (Terrence Higgins Trust), HAUK 61 (HIV Scotland).

³¹⁰ HAUK 57.

³¹¹ Q 244. See also Q 901 (Professor Graham Hart), Q 493 (Dr Simon Barton).

³¹² Q 262.

³¹³ Q 124.

³¹⁴ Q 263.

³¹⁵ HAUK 57 (African Health Policy Network).

³¹⁶ HAUK 9 (LSL Alliance).

³¹⁷ See, for example, HAUK 63 (MedFASH), HAUK 35 (Royal College of Nursing), HAUK 19 (Department of Health).

182. The need for political leadership in this expansion is crucial.³¹⁸ The Government need to demonstrate the same boldness shown in developing testing within antenatal and GUM clinics. We have seen some evidence of such leadership, in the funding of pilot studies looking at the expansion of testing in primary care, medical specialisms and the community³¹⁹, and the inclusion of a late diagnosis indicator within the draft Public Health Outcomes Framework (see paras 324 to 327). More widespread commitment is essential.
183. A number of testing guidelines offer a clear framework for expansion outside of traditional testing settings.
184. Professionally developed guidelines, the *UK National Guidelines for HIV Testing 2008*³²⁰, were widely endorsed.³²¹ The main thrust of these guidelines is the need for increased levels of testing across a number of settings. This includes consideration of the routine offer and recommendation of a HIV test for new GP registrants and general medical admissions in high-prevalence areas. They also stress the importance of frequent testing, particularly for those at highest risk. (See Box 2)

BOX 2

2008 Testing Guidelines—Main Recommendations

A. Universal HIV testing—which is the routine offer and recommendation of testing—is recommended in:

- (1) GUM or sexual health clinics
- (2) antenatal services
- (3) termination of pregnancy services
- (4) drug dependency programmes
- (5) healthcare services for those diagnosed with tuberculosis, hepatitis B, hepatitis C and lymphoma.

B. An HIV test should be considered in the following settings where diagnosed HIV prevalence in the local population exceeds 2 per 1000 of population

- (1) all men and women registering in general practice
- (2) all general medical admissions.

The introduction of universal HIV testing in these settings should be thoroughly evaluated for acceptability and feasibility and the resultant data made available to better inform the ongoing implementation of these guidelines.

C. HIV testing should be also routinely offered and recommended to the following patients:

- (1) all patients presenting for healthcare where HIV, including primary HIV infection, enters the differential diagnosis
- (2) all patients diagnosed with a sexually transmitted infection
- (3) all sexual partners of men and women known to be HIV-positive

³¹⁸ HAUk 63 (MedFASH), HAUk 64 (Terrence Higgins Trust), HAUk 53 (British HIV Association).

³¹⁹ HAUk 19 (Department of Health).

³²⁰ British HIV Association, British Association for Sexual Health and HIV, British Infection Society, *UK National Guidelines for HIV Testing 2008, op. cit.*

³²¹ Q 17 (Dr Valerie Delpech), HAUk 53 (British HIV Association), HAUk 47 (National AIDS Trust), HAUk 57 (African Health Policy Network), HAUk 74 (Gilead Sciences).

- (4) all men who have disclosed sexual contact with other men
- (5) all female sexual contacts of men who have sex with men
- (6) all patients reporting a history of injecting drug use
- (7) all men and women known to be from a country of high HIV prevalence (>1%)
- (8) all men and women who report sexual contact abroad or in the UK with individuals from countries of high HIV prevalence.

185. Another set of guidelines, published in March 2011 by NICE, seek to increase testing rates amongst black African communities and MSM.³²² These also received widespread support.³²³ The NICE documents refer to the 2008 guidelines as the “national standard”, and use them as the basis for their suggestions. One novel theme within the NICE guidelines is the call for local strategies for HIV testing to be developed, to overcome barriers to more widespread testing. They also stress the importance of engaging the community, such as through the use of rapid tests, to take testing out of clinical settings.
186. As part of this debate, the Government funded pilot studies to examine the case for expansion in line with these guidelines. These pilots were successful, finding that expansion was feasible and acceptable to both patients and staff.³²⁴ The Minister for Public Health made clear that they were so successful that, in five out of eight pilot areas, the initiatives continued to be funded after the end of the pilot period.³²⁵ The interim report of the pilots, *Time to Test*, produced a series of recommendations.³²⁶ Like the professional and NICE guidelines, it called for routine testing in general practice and medical admissions (most pressingly in high-prevalence areas) and for the expansion of community testing services.
187. The Department of Health have commissioned three pilot sites to analyse the cost-effectiveness of different models of routine HIV testing, following on from the initial *Time to Test* research.³²⁷ This will improve the evidence base in this area. Nonetheless, the data so far is clear. Although the recommendations are estimated to cost around £8.4m per year³²⁸, both Dr Keith Radcliffe and Dr Ian Williams stressed that available figures showed them to be cost-effective according to international standards, in terms of both earlier diagnosis and the prevention of disease.³²⁹

³²² National Institute for Health and Clinical Excellence, *NICE public health guidance 33: increasing the uptake of HIV testing to reduce undiagnosed infection and prevent transmission among black African communities living in England*; and *NICE public health guidance 34: increasing the uptake of HIV testing to reduce undiagnosed infection and prevent transmission among men who have sex with men*. Both published March 2011.

³²³ See, for example, HAUK 57 (African Health Policy Network), HAUK 50 (Halve It Coalition), HAUK 53 (British HIV Association).

³²⁴ HAUK 19 (Department of Health).

³²⁵ Q 1105.

³²⁶ Health Protection Agency, *Time to test for HIV: Expanded healthcare and community HIV testing in England, interim report*, December 2010.

³²⁷ Q 181 (Professor David Harper).

³²⁸ HAUK 97 (Health Protection Agency).

³²⁹ Q 239. Dr Radcliffe noted that the American Centers for Disease Control and Prevention believed that testing is cost-effective if one undiagnosed person is found for every 1,000 tests performed, and that “most of the pilots that have been done in novel settings have picked up HIV at a higher rate than that.” Dr Williams referred to French data, which suggested that routine testing was cost-effective where

Conclusion

188. The framework for expansion is clear. Professional and NICE guidelines, along with the interim *Time to Test* recommendations, are based on clinical expertise and evidence that cannot be readily ignored. The range of settings for routine opt-out HIV testing must expand to include new registrations in general practice and medical admissions across a range of areas. Community testing is also crucial, and such services must be bold.³³⁰ We heard, for example, that the 56 Dean Street NHS clinic in London³³¹, and Yorkshire MESMAC in Leeds³³², both delivered testing in locations such as gay saunas and bars. This provision must form part of testing strategies; as Professor Mike Kelly made clear, the scale of the public health problem means that the “nettle has to be grasped”.³³³
189. Implementation is the key. The LSL Alliance³³⁴ felt that the expansion of testing “has not been actively supported by the wider NHS at a local level across the UK”.³³⁵ Concerns about implementation were shared elsewhere.³³⁶ Cost-effectiveness, though, must be a necessary constraint on this expansion at a time of restricted public spending. As a result, the focus must be on high-prevalence areas.
190. Expansion must have political support from the Government, and financial and human resource support from commissioning bodies—whether it be Primary Care Trusts now, or local authorities under proposed new public health structures. The *Time to Test* interim report made this clear. The late diagnosis outcome indicator can be a vital tool to ensure this support and drive expansion. It should be used as such.
191. **Earlier diagnosis ensures that those infected receive timely treatment, saving money on the treatment costs of more advanced infections and preventing onward transmission of the virus. This is cost-effective in the long-term. We therefore recommend that the Government endorse both the 2008 professional testing guidelines and the 2011 NICE testing guidelines. The policies recommended within those documents, and the recommendations made in the interim *Time to Test* report by the Health Protection Agency, should be implemented.**
192. **In particular, HIV testing should be routinely offered and recommended, on an opt-out basis, to newly registering patients in general practice, and to general and acute medical admissions. This should begin with high-prevalence areas (where prevalence is greater than 2 cases per 1,000 people). HIV testing should also be made routine and opt-out in relevant specialties where conditions are associated with increased rates of HIV infection, such as TB and**

undiagnosed prevalence was around one in 1,000; a rate “very similar” to recommendations in testing guidelines.

³³⁰ See, for example, HAUk 53 (British HIV Association), HAUk 63 (MedFASH), HAUk 57 (African Health Policy Network), HAUk 62 (Scottish Government), HAUk 36 (Association of Directors of Public Health), HAUk 3 (Naz Project), HAUk 23 (LASS).

³³¹ See Appendix 5, *op. cit.*

³³² See Appendix 6, *op. cit.*

³³³ Q 336.

³³⁴ A South London dommissioning collective, covering Lambeth, Southwark and Lewisham.

³³⁵ HAUk 9.

³³⁶ Q 245 (Dr Ian Williams), HAUk 74 (Gilead Sciences).

hepatitis. Finally, testing should be expanded into the community. Local testing strategies must be put in place to facilitate this.

193. These policies should be supported with financial and human resources from commissioning bodies. HIV testing should feature prominently in local needs assessments and testing strategies in high-prevalence areas. The Government must ensure that the performance of commissioners and clinicians is monitored through regularly commissioned audits now, and the late diagnosis indicator in its Public Health Outcomes Framework in future.

Delivering change

Professional engagement

194. A major obstacle to more widespread testing seems to be with those who could offer the test.³³⁷ As AHPN and the Halve It Coalition³³⁸ said: “Patient acceptability of the offer of testing has been repeatedly demonstrated; the principal barrier appears to lie in the lack of offers of testing from healthcare professionals”.³³⁹ MedFASH felt it was “key” to change the attitudes and practice of healthcare professionals in this respect.³⁴⁰
195. One part of changing practice must be to increase the levels of knowledge and confidence amongst professionals, amongst whom there are a number of issues. For example, there is a widespread incorrect perception that “pre-test counselling” is required.³⁴¹ Though counselling may be necessary for those who test positive, given the potential psychological impact of a diagnosis, the only requirement before a test is to ensure the informed consent of the person being tested. Despite efforts—including through a letter from the Chief Medical and Nursing Officers in 2007³⁴²—to communicate this, Dr Ewen Stewart of the RCGP believed that the perception that counselling was required had been a “deterrent”.³⁴³
196. Professionals also seem to misunderstand the time it takes to conduct tests. The British Medical Association (BMA) felt that routine general practice testing was not, “entirely practicable, partly due to the time constraints within GP appointments.”³⁴⁴ However, staff we met in Brighton asserted that the average consultation lasted less than a minute.³⁴⁵ Dr Philippa Matthews, a general practitioner at the Killick Street Health Centre in London, said that, “Time is a barrier cited by people who do not know enough”.³⁴⁶
197. There are also persistent concerns about stigmatisation by healthcare professionals. NAT cited research which suggested that half of the reported instances of discrimination experienced by people living with HIV had

³³⁷ HAUK 74 (Gilead Sciences Ltd), HAUK 9 (LSL Alliance).

³³⁸ A coalition of HIV and healthcare organisations working to halve the proportion of people living with undiagnosed HIV.

³³⁹ HAUK 57 (African Health Policy Network), HAUK 50 (Halve It Coalition).

³⁴⁰ HAUK 63.

³⁴¹ HAUK 74 (Gilead Sciences), HAUK 54 (Royal College of GPs), HAUK 20 (Dr Sris Allan), HAUK 57 (African Health Policy Network), HAUK 59 (NAHIP).

³⁴² HAUK 19 (Department of Health).

³⁴³ Q 700.

³⁴⁴ HAUK 76.

³⁴⁵ See Appendix 4: Visit to Brighton, 15 March 2011.

³⁴⁶ Q 693.

involved healthcare professionals.³⁴⁷ Such stigmatisation can deter people from testing and accessing treatment.³⁴⁸ This is very concerning given the benefits of timely diagnosis.

198. There is, therefore, a pressing need to improve the levels of knowledge of HIV amongst professionals.³⁴⁹ The Minister stressed that, as part of public health being increasingly prioritised, “sitting alongside that is training, educating and supporting health professionals ...”³⁵⁰
199. There have been a number of developments to this end. At government-level, the Department of Health previously funded MedFASH to develop a resource pack, *Tackling Testing*, to support non-specialist healthcare professionals in offering HIV testing.³⁵¹ This has been followed up with a three-year project grant to develop resources for testing in primary care.³⁵²
200. Elsewhere, the Royal College of GPs has developed a *Six Step Guide to HIV testing in primary care*, with HIV testing also forming part of the curriculum for its Introductory Certificate in Sexual Health.³⁵³ Meanwhile, researchers at the Chelsea and Westminster hospital have developed a Sexually Transmitted Infection Foundation course focusing on increasing testing in primary care, which more than 12,000 GPs have completed over the last decade.³⁵⁴ Sexual Health in Practice³⁵⁵ has worked to train GPs to offer more tests to those whose activities may put them at risk of, or who display symptoms potentially linked to, HIV—important skills outside of high-prevalence areas.³⁵⁶
201. Nevertheless, it is clear that the extent of education and training on HIV and AIDS is insufficient. There are significant misconceptions at work, which manifest in insufficient testing levels outside of traditional settings and persisting problems of stigma. This cannot continue, especially not in primary care. As Dr Philippa Matthews made clear, testing comes within the general practitioner’s “contractual work of looking after people with illnesses”.³⁵⁷ Improving the knowledge and confidence levels of practitioners in dealing with HIV is an integral part of changing the culture around testing.
202. The reluctance to test of healthcare professionals, and in particular GPs, must cease to be a barrier to more widespread testing. We welcome the Government’s three-year project grant to MedFASH to develop resources for those in primary care, and the work of the Royal College of GPs and others in this area. However, the Government, the Royal Colleges and other professional associations such as the BMA must better engage with this agenda and expand their efforts, in order to develop a culture where testing for HIV is a normal part of medicine. By bringing testing into the

³⁴⁷ HAUK 47.

³⁴⁸ Q 581 (Jim Jewers).

³⁴⁹ HAUK 36 (Association of Directors of Public Health), HAUK 53 (British HIV Association).

³⁵⁰ Q 1109.

³⁵¹ HAUK 19 (Department of Health).

³⁵² Q 1107 (Anne Milton MP).

³⁵³ HAUK 54 (Royal College of GPs).

³⁵⁴ See Appendix 5, *op.cit.*

³⁵⁵ A training programme to develop the expertise of healthcare professionals in sexual health services.

³⁵⁶ HAUK 7.

³⁵⁷ Q 695.

mainstream, we can tackle the misinformation and stigmatisation related to HIV, which can yield significant benefits for public health.³⁵⁸

203. This will take time. Dr Keith Radcliffe outlined in evidence that, “we are in the middle of a long process ... that is going to take several years”.³⁵⁹ This does not mean that change has to wait. The local testing strategies called for in NICE guidelines (see para 185) offer an ideal opportunity for professional bodies, clinicians and commissioners to work together to improve professional confidence around testing.
204. **HIV testing outside of GUM and antenatal clinics must become more widespread. Professionals, most notably general practitioners, must become more confident and competent in offering and administering tests. Training and education are important tools to use to achieve this; they should form an important part of local testing strategies. Such training must incorporate efforts to address HIV-related stigma, and develop understanding of the needs of people living with HIV.**
205. **Practitioners must also be more confident in identifying those at risk of HIV and those with symptoms of infection. Undergraduate training and ongoing professional development for medical practitioners should stress the importance of these skills. This is particularly so for specialists dealing with hepatitis and tuberculosis, where co-infection with HIV is more common.**

Patient engagement

206. Although we have stressed the importance of changing the culture amongst healthcare professionals, the public more generally must be encouraged to be tested.³⁶⁰ In addition, those at high risk must be encouraged to test more frequently.³⁶¹
207. One part of this encouragement involves tackling stigma amongst healthcare professionals, as discussed above. However, patients must also be informed and confident when navigating the healthcare system. BASHH and the Royal College of Physicians called for a range of measures to improve levels of knowledge, including training and support to build self-confidence in medical settings.³⁶²
208. Testing can be made acceptable in other ways. Home testing is one obvious method. At present, the HIV Testing Kits and Services Regulations 1992 bans the supply of home testing kits, meaning that they cannot be legally supplied. Despite this, home testing equipment is available over the internet: one survey showed that 0.5% of the 180,000 people surveyed (900 people) had their last test at home, whilst 5.9% said home testing would be their preferred method in the future.³⁶³ There are, though, no means of regulation for authorities in the United Kingdom. Professor David Harper of the Department of Health acknowledged that the ban was “difficult to

³⁵⁸ HAUK 50 (Halve It Coalition), Q 264 (Ruth Lowbury).

³⁵⁹ Q 264.

³⁶⁰ Q 240 (Ruth Lowbury).

³⁶¹ See, for example, Q 848 (Professor Noel Gill).

³⁶² HAUK 55.

³⁶³ HAUK 64 (Terrence Higgins Trust).

enforce.”³⁶⁴ One of the main arguments against the ban is, therefore, a pragmatic one. Ruth Lowbury referred to a “train that is already running along the tracks”, and called for legalisation and regulation to “minimise the damage”.³⁶⁵

209. Additionally, home testing would give people greater responsibility and control over their own health. Outlining the view of a number of contributors, Dr Ian Williams said that “people should be given the opportunity to take control of their lives and find out about their problems”.³⁶⁶ Home testing could also mean earlier access to testing—one survey found that 35% of those canvassed who were infected with HIV thought they would have been diagnosed earlier if home testing had been available.³⁶⁷
210. Overall, patient engagement is crucial. If too few people come forward for testing, then developments within hospitals and general practice will fail to effect widespread change. We heard during our visit to the Homerton University Hospital, for example, that encouraging the partners of HIV-positive black African women to test was an ongoing challenge.³⁶⁸
211. Education and training is critical to this engagement. It can ensure that people are aware of the benefits of knowing their status, forming part of the cultural shift in which HIV testing becomes a normal part of visiting healthcare services.³⁶⁹ It can also ensure that people are more aware of when they are at risk of HIV, allowing for more timely testing and diagnosis. We accept that this change will not be immediate. Dr Keith Radcliffe felt it was one that would take place a “few years” after culture changes amongst healthcare professionals.³⁷⁰
212. The cultural shift must include a legal and regulated system of home testing. The Minister for Public Health did not believe that the alternative—unregulated access to potentially inaccurate tests online—was sustainable³⁷¹, and nor do we. There are legitimate concerns about getting those who test at home to access services³⁷², but regulation would ensure that messages about the importance of accessing care are communicated.
213. **Encouraging people to test, through the provision of education, training and support, can have significant benefits for the public. We support the development of local testing strategies, recommended within NICE testing guidelines. Equipping people with the knowledge and desire to get tested should form an integral part of those strategies.**
214. **The ban on HIV home testing kits, as laid out in the HIV Testing Kits and Services Regulations 1992, is unsustainable and should be repealed. A plan should be drawn up, in consultation with clinicians, patients, voluntary organisations and professional associations, to**

³⁶⁴ Q 181.

³⁶⁵ Q 248. See also HAUk 43 (TCell).

³⁶⁶ Q 247. See also HAUk 43 (TCell), HAUk 64 (Terrence Higgins Trust), Q 249 (Ruth Lowbury).

³⁶⁷ Q 121 (Sir Nick Partridge).

³⁶⁸ See Appendix 5, *op.cit.*

³⁶⁹ HAUk 63 (MedFASH), HAUk 47 (National AIDS Trust), Q 240 (Ruth Lowbury).

³⁷⁰ Q 264.

³⁷¹ QQ 1110–1112.

³⁷² Q 249 (Ruth Lowbury), Q 530 (Dr Stuart Gibson), Q 531 (Nathaniel Ault).

license kits for sale with appropriate quality control procedures in place. The licensing regime must make sure that the tests are accurate, and that the process gives comprehensive advice on how to access clinical and support services in order that those who test positive get the care that they need.

215. We have called for a radical cultural change, where HIV testing is a normal part of medical care. This will not come overnight. Nonetheless, change has to begin now. The adoption of our recommendations would result in significant progress towards routine and widespread testing, reducing the transmission, and consequently the spread, of HIV.

CHAPTER 7: THE RIGHT TREATMENT

216. Over the last 25 years, the development of antiretroviral therapies has transformed the nature of treatment.³⁷³ This treatment is an integral part of the response to HIV, but it is expensive. Services in England cost £760m in 2009–10³⁷⁴, with antiretroviral drugs alone estimated to cost around £5,500 per person per year.³⁷⁵ Furthermore, it is not problem-free. Side-effects can include kidney problems³⁷⁶, osteoporosis³⁷⁷ and fat distribution disorders.³⁷⁸ It is also vital that treatment is adhered to consistently. This keeps viral load controlled. Poor adherence increases the risk of treatment failure and the development of antiretroviral resistance. This must be closely monitored (see para 228).
217. Given these constraints, we must not simply accept the growing numbers of those becoming infected and moving onto treatment. We must increase the focus on prevention. This means that testing must be more widespread, and preventive interventions across a variety of areas must receive more support at all levels.
218. Early diagnosis is important to avoid the poorer outcomes of late treatment and to reduce transmission rates. Interaction with specialist services also offers the chance to provide continued advice on behaviour change, reducing risk behaviours. All of this benefits the health of the patient, as well as the public more generally. Consequently, commissioning and delivering accessible, effective and well-tolerated care is of critical importance.³⁷⁹

Commissioning effective, efficient treatment

219. HIV treatment is commissioned at present by Primary Care Trusts. Under proposed reforms, HIV treatment and care will be commissioned at a national level by the NHS Commissioning Board, rather than by local NHS clinical commissioning groups.³⁸⁰ Owing to the uneven prevalence of HIV infection across the country, the Government believes that there is a need to prevent disproportionate costs falling on particular clinical commissioning groups, and that national commissioning will secure efficiencies from procuring drugs and services at scale.³⁸¹
220. The London Specialised Commissioning Group, which has worked to pool HIV commissioning across the capital, set out how commissioning on a broader scale has been used to successfully produce efficiencies, economies of scale and uniform standards of treatment access across London.³⁸² It suggested that this highlighted the potential of commissioning on a greater scale.
221. National commissioning of HIV treatment has been broadly welcomed. MedFASH suggested that, as a relatively high-cost, low volume service, HIV

³⁷³ See, for example, Q 446 (Professor Jonathan Weber).

³⁷⁴ HAUK 94 (Department of Health).

³⁷⁵ HAUK 97 (Health Protection Agency)

³⁷⁶ See Appendix 4, *op. cit.*

³⁷⁷ Q 539 (Silvia Petretti).

³⁷⁸ Q 501 (Simon Barton).

³⁷⁹ Q 404 (Mary Kerr).

³⁸⁰ HAUK 19.

³⁸¹ *ibid.*

³⁸² HAUK 51.

treatment was more appropriately commissioned at a national level.³⁸³ These views were echoed by a number of other witnesses.³⁸⁴

222. Whilst there was support for HIV commissioning at a national scale, commissioners felt that such services also needed to be responsive to local needs.³⁸⁵ The need for structures, such as regional networks, to allow for local tailoring and accountability was highlighted by contributors such as MedFASH³⁸⁶ and NELNET.³⁸⁷
223. **HIV treatment and care services should be commissioned at a national level, given their high cost and the variation in HIV prevalence nationwide. To ensure commissioning is responsive to differing patterns of need across the country, regional treatment and prevention service networks, appropriately supported and resourced by the Government, should be established.**

Drug procurement

224. It is estimated that around two-thirds of the annual costs of treatment and care comes from the procurement of drug therapies.³⁸⁸ Securing efficiencies in this area could have a major impact in limiting the overall costs of treating HIV.
225. Currently, HIV drugs are procured locally rather than nationally.³⁸⁹ Within London, commissioners took a decision to collectively procure drugs, through the London HIV Consortium, to secure economies of scale.³⁹⁰ Similar arrangements have emerged in other parts of the country, including Greater Manchester.³⁹¹ Simon Williams, Divisional Director of the London Specialised Commissioning Group, stated that: "We have certainly found a benefit from using a pan-London approach for procuring drugs and I think there is a lesson to be had from that."³⁹² Clinicians at the Chelsea and Westminster hospital suggested that purchasing drugs nationally could secure even greater savings.³⁹³
226. When commissioning, it should be borne in mind that drugs need not only be clinically effective; they must also be tolerable to take. As Mary Kerr of ViiV Healthcare made clear, "tolerability is one of the major drivers of adherence ... adherence is one of the major drivers of efficacy".³⁹⁴ Positively UK was concerned that a short-term pursuit of cost savings could impact upon this through the purchasing of cheaper and less well-tolerated drugs. This, it felt, would be counter-productive, leading to poor adherence and increased costs through expensive inpatient care in the longer-term.³⁹⁵

³⁸³ HAUK 63.

³⁸⁴ See, for example, HAUK 55 and 73 (British Association for Sexual Health and HIV and the Royal College of Physicians), HAUK 64 (Terrence Higgins Trust), HAUK 47 (National AIDS Trust), HAUK 24 (NAM).

³⁸⁵ Q 750 (Justine Womack, Office for Sexual Health South West).

³⁸⁶ HAUK 63.

³⁸⁷ HAUK 6. NELNET is a North East London commissioning body.

³⁸⁸ See, for example, Q 748 (Simon Williams).

³⁸⁹ HAUK 94 (Department of Health).

³⁹⁰ *ibid.*

³⁹¹ HAUK 82 (Sarah Stephenson, Greater Manchester Sexual Health Network).

³⁹² Q 749.

³⁹³ See Appendix 5, *op. cit.*

³⁹⁴ Q 404.

³⁹⁵ HAUK 37.

227. Adherence is vital in managing the HIV epidemic; around 95% adherence is needed for treatment to be effective.³⁹⁶ Without this, viral resistance can develop and more complex and expensive treatments need to be provided. Recent studies have suggested that up to 19% of new HIV infections in the United Kingdom may show some level of resistance to drug treatments.³⁹⁷ The possible transmission of drug resistant infections is an emerging problem.
228. Greater uptake of antiretrovirals, for both treatment and prevention, has the potential to impact on the emergence and transmission of drug resistant forms of HIV. Viral resistance is currently monitored by the UK HIV Drug Resistance Database, funded by a grant from the Medical Research Council. This work is of increasing importance, and must continue to be supported. Alongside such efforts, viral resistance is best managed by commissioning well-tolerated treatments.
229. **Existing procurement arrangements, where antiretroviral drugs are locally procured, mean that drug prices vary across the country. This should be changed. Antiretroviral drug treatments should be procured on a national scale. This offers the potential for significant savings by making use of the purchasing power and economy of scale of the National Health Service, as well as standardising prices nationwide.**
230. **The costs of HIV treatment are best managed by purchasing well-tolerated, easily adhered to drug regimens. This reduces the likelihood of incurring the much higher costs of inpatient care which result from poor adherence to treatment. Under national commissioning structures, commissioners must procure drugs that allow clinicians the flexibility to prescribe regimes that best serve this long-term view.**
231. **Continued monitoring of viral resistance to drug treatments, currently carried out through the UK HIV Drug Resistance Database, is essential.**

Integration of HIV and wider STI services

232. Under proposed reforms to the NHS, HIV treatment will be commissioned by the national NHS Commissioning Board, whilst prevention and testing services will be commissioned by local authorities. There are significant concerns about this division in commissioning responsibility. Summit House suggested that the split will present difficulties in getting primary care providers to engage with HIV testing³⁹⁸, whilst NAHIP noted that commissioning routes for 'treatment as prevention' (see paras 147 to 155) will become confused under the proposed reforms.³⁹⁹
233. The reforms separate responsibility for HIV prevention from responsibility for HIV treatment. Gilead Sciences suggested that this could disincentivise prevention, testing and early diagnosis, as those commissioning such services

³⁹⁶ D. L. Paterson *et al.*, *Adherence to protease inhibitor therapy and outcomes in patients with HIV infection*, *Annals of Internal Medicine*, 2000, pp 21–30.

³⁹⁷ Buckton AJ *et al.*, *Increased detection of the HIV-1 reverse transcriptase M184V mutation using mutation-specific minority assays in a UK surveillance study suggests evidence of unrecognised transmitted drug resistance*. *HIV Medicine*, advance online publication, 2010.

³⁹⁸ HAUk 78.

³⁹⁹ HAUk 59.

would not accrue any financial benefit from reduced treatment costs should the number of new infections decline.⁴⁰⁰

234. The reforms may lead to further divisions in the commissioning of STI services. Local authorities will be responsible for commissioning screening, prevention and treatment services for STIs, through open-access GUM services. The only exception to this will be HIV treatment, which will be commissioned at the national level. Sexual health and HIV services should be integrated; such integration supports effective prevention and treatment, as well as facilitating high-quality research. NHS services in many parts of the country have taken steps in recent years to promote the integration of sexual health and HIV services, Justine Womack, Head of the Office for Sexual Health in the South West⁴⁰¹, noted that the integrated model there supported effective prevention work.⁴⁰²
235. There are therefore concerns about the potential for fragmentation of treatment services under the proposed reforms, which could increase costs and undermine the skill base of staff, jeopardising the holistic approach to treatment pursued in recent years.⁴⁰³ This is an important issue. HIV transmission is more likely when individuals are suffering from other STIs, and so diagnosing and treating those infections is an important element of HIV prevention work. The diagnosis of another STI is also an indicator of unsafe sexual behaviour, which may lead to a risk of HIV transmission in future. The diagnosis of STIs thus provide a useful opportunity for HIV prevention counselling to be provided. Contributions from BHIVA⁴⁰⁴ and the HIV Pharmacy Association⁴⁰⁵ highlighted the need for joint working arrangements and strong governance to prevent fragmentation.
236. **We recognise the concerns arising from the proposed split in commissioning responsibility for HIV prevention, treatment and social care services. We recommend that the Department of Health place a duty upon those commissioning HIV services to support the integration of all HIV services in their commissioning decisions.**
237. **We also recognise the importance of prevention efforts in relation to other STIs, and the role that they can play in preventing the spread of HIV. The integration of STI and HIV treatment services, therefore, is essential for prevention efforts. We share the concerns of those who suggest that the proposed NHS reforms may increase the fragmentation of services. We recommend that the Department of Health place a duty to promote service integration upon those commissioning sexual health and HIV services.**

Delivering treatment and care

238. Treatment services are delivered via medical specialities such as GUM or Infectious Diseases (ID). GUM services, where a large proportion of outpatient treatment is undertaken, also provide diagnosis, treatment and prevention services for STIs. Care in these settings, involving multiple

⁴⁰⁰ HAUK 74.

⁴⁰¹ An NHS South West sexual health commissioning body.

⁴⁰² Q 741.

⁴⁰³ HAUK 47 (National AIDS Trust).

⁴⁰⁴ HAUK 53.

⁴⁰⁵ HAUK 48. The HIV Pharmacy Association is a professional body for pharmacists and technicians working in HIV-related specialities.

disciplines, has been very successful. We saw this first-hand in Brighton⁴⁰⁶, London⁴⁰⁷ and Leeds.⁴⁰⁸ Treatment outcomes are widely acknowledged as excellent⁴⁰⁹; in London, 90% of patients had an undetectable viral load within one year of starting therapy.⁴¹⁰ These services therefore have an important role to play in prevention, as well as caring for those infected.

239. Nevertheless, services are under pressure for a number of reasons. Principally, the patient cohort is outgrowing service capacity, as patient numbers have tripled since 2000 (see para 30).⁴¹¹ Dr Ian Williams of BHIVA said simply, “I think the model of care at the moment is unsustainable ... There is not the resource capacity within the current system to allow the current model to continue.”⁴¹² With increasing life expectancy, HIV is now also a “long-term” condition, requiring decades of care.⁴¹³ An ageing cohort brings new clinical challenges.⁴¹⁴ Care must also be responsive to its users; an element which the Metro Centre⁴¹⁵ believed had been “fundamental” to developing trust in services amongst the HIV community in the past.⁴¹⁶
240. As the number of those living with HIV continues to increase, problems of capacity and cost can only worsen. Changes must be made to maintain the high standard of services.

Recommended treatment developments

Developing standards of care for HIV and AIDS

241. At present, guideline standards for HIV treatment and care are outlined in documents written and published by professional bodies.⁴¹⁷ They are not binding documents, but do identify best practice in order to guide clinicians and influence commissioning practice. Performance against those standards is audited by the same bodies that developed them. The Minister for Public Health noted that they are “widely used ...”⁴¹⁸
242. Although existing standards are “internationally recognised”⁴¹⁹, there is a role for broader and more persuasive treatment standards.⁴²⁰ Under proposals for public health reform, the development of quality standards is expected to be “a significant part” of the role of NICE.⁴²¹ Professor Mike Kelly of NICE was convinced that it had the expertise to produce standards for HIV and

⁴⁰⁶ See Appendix 4, *op. cit.*

⁴⁰⁷ See Appendix 5, *op. cit.*

⁴⁰⁸ See Appendix 6, *op. cit.*

⁴⁰⁹ See, for example, HAUK 55 (British Association for Sexual Health and HIV and the Royal College of Physicians), HAUK 64 (Terrence Higgins Trust), HAUK 53 (British HIV Association), HAUK 51 (London Specialised Commissioning Group), HAUK 47 (National AIDS Trust).

⁴¹⁰ Health Protection Agency, *HIV in the United Kingdom (2010 Report)*, *op. cit.*

⁴¹¹ *ibid.*

⁴¹² Q 282. See also HAUK 54 (Royal College of GPs), HAUK 36 (Association of Directors of Public Health), HAUK 64 (Terrence Higgins Trust).

⁴¹³ See, for example, HAUK 64 (Terrence Higgins Trust), HAUK 74 (Gilead Sciences), HAUK 24 (NAM), Q 404 (Lisa Bright).

⁴¹⁴ Q 469 (Dr Sheena McCormack), Q 110 (Sir Nick Partridge).

⁴¹⁵ A gay, lesbian and transgender community sexual health organisation.

⁴¹⁶ HAUK 21.

⁴¹⁷ British HIV Association, *Standards for HIV Clinical Care*, March 2007.

⁴¹⁸ Q 1113.

⁴¹⁹ HAUK 53 (British HIV Association).

⁴²⁰ HAUK 76 (British Medical Association), HAUK 47 (National AIDS Trust), Q 506 (Dr Simon Barton).

⁴²¹ Q 315 (Professor Mike Kelly).

AIDS if called upon by the Government.⁴²² He said it was an “anomaly” that NICE had only done work around HIV testing.⁴²³

243. Any standards cannot focus solely on medical care needs. There is a disproportionate prevalence of psychological problems, such as depression and anxiety, amongst those with HIV.⁴²⁴ Mental health services can help patients cope with HIV-related stigma, which without support can cause them to hide their status and mean that they do not keep up with drug regimes.⁴²⁵ Body and Soul suggested that 17% of service users reported that an inability to disclose their status had been a barrier to adherence.⁴²⁶ Mental health services can work to boost adherence, better managing viral load and thus reducing onward transmission.⁴²⁷
244. However, such services are often neglected. TCell⁴²⁸ considered them the “poor relation” of services for those with HIV.⁴²⁹ In light of this, various professional bodies are putting together psychological care standards for those with HIV.⁴³⁰ Given the many benefits of keeping patients adhering to therapy, and the individual benefits drawn from improved mental health, it is important that these are not ignored.
245. Social care needs, which the Association of Directors of Adult Social Services and the Local Government Association called the “critical partner in the care pathway”,⁴³¹ must also be catered for.⁴³² We saw in Leeds, during our time with Yorkshire MESMAC and Leeds Skyline, the important role that social care can play for patients.⁴³³
246. Given these broad needs, the development of quality standards is a compelling idea. They could provide a clear framework for action, and serve as a valuable source of guidance at a time of considerable change. By encompassing medical, social and psychological care needs, they could help to ensure more integrated treatment and care services for those with HIV, including interventions at an individual level to prevent onward transmission. The Minister for Public Health was not sure that “more is needed from NICE” given the quality of existing guidelines.⁴³⁴ However, Professor Mike Kelly noted the “fundamentally important catalytic effect” such guidance could have.⁴³⁵ We agree that NICE guidelines would be more persuasive, and would be a positive step.
247. **HIV treatment and care standards have an important role to play in guiding commissioners and clinicians in a complex area. We recommend that the Government commission NICE to develop treatment and care standards for HIV and AIDS. These should be developed in association**

⁴²² Q 340.

⁴²³ Q 344

⁴²⁴ Q 275 (Dr Ian Williams), Q 486 (Dr Stuart Gibson).

⁴²⁵ HAUK 37 (Positively UK).

⁴²⁶ HAUK 22.

⁴²⁷ HAUK 64 (Terrence Higgins Trust), HAUK 47 (National AIDS Trust), HAUK 22 (Body and Soul).

⁴²⁸ A HIV patient support organisation.

⁴²⁹ HAUK 43. See also Appendix 6, *op. cit.*

⁴³⁰ HAUK 90 (Dr Stuart Gibson, Faculty for HIV and Sexual Health, British Psychological Society).

⁴³¹ HAUK 69.

⁴³² See HAUK 64 (Terrence Higgins Trust), HAUK 22 (Body and Soul), HAUK 37 (Positively UK).

⁴³³ See Appendix 6, *op. cit.*

⁴³⁴ Q 1113.

⁴³⁵ Q 330.

with people living with and affected by HIV, along with service providers, drawing upon existing treatment guidelines.

248. They must take into account psychological and mental health needs, and social care needs more broadly. They should also reflect the value of interventions from healthcare professionals, such as advice on reducing risk behaviours, in preventing onward transmission of the virus. This should happen immediately, as the required expertise is already in place.

Ending migrant charging regulations

249. NHS services are not provided free of charge to all of those accessing care in England. Those not ordinarily resident in the United Kingdom may incur a charge for their care under the National Health Service (Charges to Overseas Visitors) Regulations 1989. Charges do not apply if a visitor has been “lawfully” resident for one year, or if any specified exemptions apply.⁴³⁶ These are laid out in the Charging Regulations and guidance on their implementation, and are set out in Box 3.

BOX 3

Exemptions from Charging and Safeguards

The Charging Regulations, and Department of Health guidance on their implementation, include a number of exemptions from charging and safeguards to prevent serious suffering. These include:

- Access to free NHS treatment for asylum seekers as long as their application and any appeal remain current;
- Continuation of an existing course of treatment even if the asylum application and any appeal fails, up until a person is deported or leaves the country (so HIV treatment once started by an asylum seeker is never withdrawn). It is for a clinician to determine what constitutes a particular course of treatment;
- Immediately necessary or other urgent treatment should not be delayed irrespective of a person’s inability to pay (although not free, guidance makes clear that treatment should take place even without advance payment), and that decisions on level of urgency are clinical only. HIV treatment must be considered as immediately necessary.⁴³⁷

Given the exemptions set out above, charges would usually only apply to HIV treatment for undocumented migrants and failed asylum seekers if HIV was diagnosed once a visa had run out or after all asylum appeals had failed.⁴³⁸

There are also specific categories of services exempt from all charges, which are laid out in Regulation 3 and in an annex at Schedule 1. These include infectious diseases such as tuberculosis and measles, but do not include HIV. It is set out that the treatment of STIs is free of charge for all; for HIV, though, this only extends to testing and associated counselling. As a result, HIV treatment must be paid for by overseas visitors not otherwise covered by one of the charging exemptions.

⁴³⁶ HAUk 70 (Department of Health).

⁴³⁷ *ibid.*

250. The result of these Regulations and associated guidance is that, for those liable to pay, HIV testing and any related counselling is provided free, but subsequent treatment and care is not.⁴³⁹ The Government do not collect data on the numbers of people affected, but it is estimated to be between 660 and 1000 people.⁴⁴⁰

Is the policy justifiable?

251. Professor David Harper of the Department of Health believed that, where people are “in the system”, the risk of onward transmission was, “addressed, at least in part, by testing and advice. Then, one would expect these people will be leaving the country”.⁴⁴¹ The Department of Health also argued that free treatment could lead to “health tourism”—people coming to the United Kingdom for the purpose of receiving HIV treatment. It stressed that it received regular reports of this happening, though failed to quantify its scale.⁴⁴² The Minister for Public Health, however, did not affirm this contention.⁴⁴³
252. There are a number of arguments against the policy. One is that it does not best serve the interests of public health. Dr Ian Williams of BHIVA believed that the public health case against charging was “overwhelming”.⁴⁴⁴ In the light of evidence that treatment reduced infectivity, the African Health Forum called the policy “absurd”.⁴⁴⁵ The Minister for Public Health in fact acknowledged that, “we need to bear in mind the public health implications of people not being able to receive treatment who are HIV-positive.”⁴⁴⁶
253. There is also an economic case for offering treatment regardless of immigration status. Deborah Jack of NAT stressed that “the cost of someone getting very sick without treatment is a lot higher than keeping them well on antiretrovirals”⁴⁴⁷, for which reason Dr Ian Williams called the policy “madness”.⁴⁴⁸
254. Furthermore, there seems to be little real evidence of “health tourism”.⁴⁴⁹ Dr Ian Williams stressed that there was “no evidence” of health tourism in a survey of BHIVA’s members.⁴⁵⁰ Deborah Jack drew attention to the fact that, although treatment was free elsewhere in the United Kingdom, “we don’t see big flows of migrants over the borders to Scotland, Wales and Northern Ireland, which if this myth of health tourism were true would happen.”⁴⁵¹
255. So there are clear ethical and economic objections to the system. But most damningly of all, it does not work in practice. The extent to which charges

⁴³⁸ *ibid.*

⁴³⁹ HAUk 70 (Department of Health).

⁴⁴⁰ HAUk 64 (Terrence Higgins Trust).

⁴⁴¹ Q 194.

⁴⁴² HAUk 94.

⁴⁴³ Q 1117.

⁴⁴⁴ Q 300.

⁴⁴⁵ HAUk 81.

⁴⁴⁶ Q 1119.

⁴⁴⁷ Q 135.

⁴⁴⁸ Q 299.

⁴⁴⁹ See National AIDS Trust, *The Myth of HIV Health Tourism*, October 2008.

⁴⁵⁰ Q 300.

⁴⁵¹ Q 135.

are pursued is a matter for individual hospitals.⁴⁵² Dr Ian Williams outlined that, in reality, this meant that treatment is given, charges are sought (from patients who cannot afford them), before then being written off—“a constant circle of nonsense”.⁴⁵³

256. Overall, the policy is unjustifiable. It deters a high-prevalence group from testing, and misses an opportunity to reduce infectivity through treatment, with only anecdotal evidence to support it. Most importantly, it simply does not work. Those tasked with caring for patients are caught up in a fiction that fails all of those involved. This is done for an amount of money that the Government does not even monitor; the Minister noted that, though there are estimates of costs recovered, “I would not even quote them, because I think the truth of the matter is we do not really know”.⁴⁵⁴
257. **Charging people for their HIV treatment and care is wrong for public health, practical and ethical reasons. We recommend that HIV should be added to the list of conditions in the National Health Service (Charges to Overseas Visitors) Regulations 1989, for which treatment is provided free of charge to all of those accessing care, regardless of residency status.**

Changing the model of care

258. Clear standards of care, and equitable access to services, are the base for further developments in how services are delivered. Any change must acknowledge the range of needs of HIV patients.⁴⁵⁵ Some patients are on stable treatment regimes, without any major complications. Others have more complex issues due to factors such as drug resistance or co-infections. Over time, developments in antiretroviral therapies have led to increasing numbers of stable patients living with HIV free of symptoms, with a significant decline in the number of people whose infection has progressed to AIDS (see para 17).
259. In developing the model of care, the aim must be to manage stable patients who have a good quality of life in the most efficient way possible, freeing up capacity for those with more complex needs. At a time of stretched resources, any savings that can be made without compromising patient care must also be supported.
260. In any reformed system, all patients must, of course, maintain regular contact with HIV specialists. From the outset, therefore, we stress that we are firmly in support of specialist treatment services continuing to be the leading location of care for those with HIV. This was a position supported across the evidence base.⁴⁵⁶ We were glad that the Minister for Public Health made clear that, “treatment is a specialist area still and will continue to be so ...”⁴⁵⁷

Improving specialist services

261. There needs to be fundamental changes to how services are organised. At the same time, there are improvements that can be made within the existing model.

⁴⁵² HAUk 70 (Department of Health).

⁴⁵³ Q 304.

⁴⁵⁴ Q 1120.

⁴⁵⁵ HAUk 24 (NAM).

⁴⁵⁶ HAUk 37 (Positively UK), HAUk 36 (Association of Directors of Public Health), HAUk 48 (HIV Pharmacy Association), HAUk 61 (HIV Scotland), HAUk 74 (Gilead Sciences).

⁴⁵⁷ Q 1115.

262. One of the simplest improvements is to offer more flexibility in the opening hours of clinics, to enable service users to get appointments in the evenings and on weekends. Though this would have resource implications, this greater flexibility would encourage access, and support service users to be economically active and in employment.⁴⁵⁸
263. Another measure is to make more use of the home delivery of drugs. Delivering drugs to patients' homes can be very convenient for patients, whilst saving time for clinic staff.⁴⁵⁹ Furthermore, because home deliveries are not subject to VAT (a curious rule), the service can deliver significant savings. In Brighton, home delivery saved around £60,000 per month⁴⁶⁰; in Greater Manchester, it saved £2.5m per year.⁴⁶¹
264. The role of 'virtual clinics'—where support is provided for stable patients online or over the phone rather than in person—is another way of freeing up capacity within specialist units and delivering care in a manner more convenient for patients.⁴⁶² For example, the *CONNECT* service offered in the Royal Sussex County Hospital in Brighton uses email and text messages to send test results.⁴⁶³ Expanding the use of cost-effective nurse-led clinics in the monitoring and assessment of patients is another means by which to reduce pressure on specialist services.⁴⁶⁴
265. Patient self-management could also be given a more prominent role. Sir Nick Partridge of the Terrence Higgins Trust called for recognition of this "direction of travel".⁴⁶⁵ The Royal College of Nursing noted that online support materials, such as the Terrence Higgins Trust *MyHIV* service, could "empower patients to access services, manage their condition and access peer support".⁴⁶⁶ NAM stressed the importance of equipping patients to "navigate the health care system".⁴⁶⁷
266. All of these measures have clear potential benefits for patients, by delivering care more flexibly and conveniently. Many can also save money, which specialist services can use elsewhere. However, such innovations will not be suitable for all; patient care must be guided by need, and not by resource imperatives. Strong oversight and protocols are essential.⁴⁶⁸ Nevertheless, given the increasing proportion of stable patients, these innovations can be applied widely to improve the delivery of treatment.
- 267. There are a number of innovative ways of delivering specialist services which should be employed more extensively. These changes benefit patients by delivering treatment more conveniently and closer to home, whilst relieving pressure on specialist clinics and allowing**

⁴⁵⁸ HAUK 36 (Association of Directors of Public Health). See also Appendix 5, *op. cit.*

⁴⁵⁹ See Appendix 5, *op. cit.*

⁴⁶⁰ See Appendix 4, *op. cit.*

⁴⁶¹ HAUK 82 (Sarah Stephenson, Greater Manchester Sexual Health Network).

⁴⁶² See, for example, HAUK 47 (National AIDS Trust), HAUK 51 (London Specialised Commissioning Group).

⁴⁶³ See Appendix 4, *op. cit.*

⁴⁶⁴ HAUK 35 (Royal College of Nursing), HAUK 45 (Tuke Institute), HAUK 51 (London Specialised Commissioning Group), HAUK 24 (NAM), HAUK 1 (Sascha Auweiler), HAUK 36 (Association of Directors of Public Health), HAUK 52 (National HIV Nurses Association).

⁴⁶⁵ Q 101.

⁴⁶⁶ HAUK 35.

⁴⁶⁷ HAUK 24.

⁴⁶⁸ HAUK 47 (National AIDS Trust), HAUK 64 (Terrence Higgins Trust).

closer working with those in primary care (see para 277). These include:

- Home delivery of antiretroviral drugs;
- Flexible evening and weekend access to services;
- Patient self-management services, including more extensive support materials;
- Virtual services such as telephone and email clinics for stable patients; and
- Nurse-led clinics.

268. Given the increasing proportion of HIV-positive people on stable treatment regimens, commissioners and clinicians (including GPs) should develop, after consultation with patients, guidelines and protocols for the expansion of the above innovations. This can free up human and financial resources for more complex elements of HIV treatment and care. Protocols must, however, provide for specialist consultants to monitor the conditions of all patients at regular intervals.

Getting GPs involved with HIV and AIDS

269. General practice is a cornerstone of healthcare in the United Kingdom. GPs are routinely involved in managing the health of millions of people across the country. This is not, though, the case for most people with HIV and AIDS. As Dr Ewen Stewart of the RCGP noted, “a lot of patients are not getting their primary care in primary care. They are getting it all at the hospital clinic.”⁴⁶⁹ This is despite the fact that the HIV cohort is an ageing one; those with HIV need good primary care to manage many of the common conditions experienced by older people.⁴⁷⁰ The present situation increases the pressure on already stretched specialist services.
270. GPs must become more involved in the care of their HIV-positive patients. There is no reason why this should not be standard practice. Many chronic conditions are already dealt with on a routine basis by general practitioners, and this must become the case for HIV. The Minister for Public Health, though supportive of specialist provision (see para 260), agreed. She said that “... there is going to need to be some good integration going back to GPs with managing people who are living for a long time with HIV alongside other long-term conditions.”⁴⁷¹ The question is how extensive a role this should be. Patient engagement will be crucial in any scenario; TCell warned against “top down edicts” in this area.⁴⁷²
271. Taking on the primary care responsibilities of a HIV-positive patient, as is the case for all others registered at a practice, is essential. This would make those in primary care more familiar with HIV, the first step on the way to making it a standard part of a GP’s role. As Dr Ian Williams of BHIVA noted, this would not reshape the nature of general practice; it would involve

⁴⁶⁹ Q 709.

⁴⁷⁰ Q 709 (Dr Ewen Stewart), HAUk 76 (British Medical Association), HAUk 36 (Association of Directors of Public Health), HAUk 64 (Terrence Higgins Trust).

⁴⁷¹ Q 1115.

⁴⁷² HAUk 43.

“asking GPs ... to deliver primary care to their patients, which is what their responsibility is”.⁴⁷³

272. The more controversial question is whether GPs should take over elements of HIV care considered ‘specialist’ at present. Involving GPs in ‘routine’ aspects of care for stable patients, for example, could reduce pressure on specialist services.⁴⁷⁴ Dr Ewen Stewart—who felt such a model had potential in high-prevalence areas—drew parallels with existing practice in rheumatology in this respect.⁴⁷⁵
273. Some were more hesitant. Dr Bill Beeby, Chairman of the Clinical and Prescribing Committee of the BMA’s General Practitioners Committee, believed that a shift would “evolve over a period of time and is not something that is going to be achieved as a sudden step”.⁴⁷⁶ NAM, though supportive of some devolution, felt that it was “overly simplistic to assume the majority of patients with HIV will eventually be managed through general practice”.⁴⁷⁷ Dr Christopher Wood⁴⁷⁸ went further. Though he believed that GP involvement was feasible in some areas, he felt that, “moving any substantial proportion of HIV care out of specialist centres is not currently viable and would be counterproductive”.⁴⁷⁹
274. Involving GPs in areas traditionally considered ‘specialist’ is an interesting proposition. It would, however, involve a fundamental shift in service provision. It could only take place over the medium- to long-term. The division and shared nature of responsibility would have to be made very clear; guidelines and protocols would be essential. Effective patient engagement would also be crucial.
275. Nonetheless, we are supportive of investigating the possibilities. We recommend that greater responsibility for the primary care needs of patients shifts to GPs, as partners alongside specialist services—as is done for many other chronic conditions. This would set in motion a change in culture, with the object of HIV becoming a condition routinely taken on by GPs.
276. There is no case for a shift in all responsibilities, given the important role that specialist services play. As Dr Keith Radcliffe of BASHH and the Royal College of Physicians made clear, the “option to send them back to the specialist centre if something untoward happens” is essential.⁴⁸⁰ In particular, it does not take away the importance of prescribing antiretroviral therapies in specialist settings, given the complexity of that task.⁴⁸¹
277. **We recommend that the Government work with specialists, GPs and patients to develop a strategy for GPs to take on shared responsibility for the care of HIV-positive patients. This work should include broader consideration of the appropriate boundaries of responsibility between primary care and specialist services. The results should form**

⁴⁷³ Q 296.

⁴⁷⁴ HAUK 64 (Terrence Higgins Trust), HAUK 47 (National AIDS Trust), HAUK 53 (British HIV Association).

⁴⁷⁵ Q 709.

⁴⁷⁶ Q 706.

⁴⁷⁷ HAUK 24.

⁴⁷⁸ A HIV consultant at North Middlesex University Hospital NHS Trust.

⁴⁷⁹ HAUK 44.

⁴⁸⁰ Q 288.

⁴⁸¹ HAUK 48 (HIV Pharmacy Association), HAUK 54 (Royal College of GPs), Q 709 (Dr Ewen Stewart).

the basis of longer-term strategies for expanding the role of GPs in the management of HIV-positive patients.

Barriers to involvement

278. Many patients are concerned about confidentiality in primary care.⁴⁸² Dr Ewen Stewart of the RCGP accepted that this perception was a problem, but did not believe that there was any “major failure of confidentiality in general practice”.⁴⁸³ In this respect, both Dr Stewart and Dr Simon Barton, Clinical Director at the Chelsea and Westminster Hospital, noted that GPs are under the same professional obligations in relation to confidentiality as practitioners elsewhere.⁴⁸⁴ Nonetheless, Dr Stewart felt it was important for general practice to make clear to patients the importance that practices attached to confidentiality; it was important to “do the PR exercise with the patients but also with the secondary care units and some of the HIV patient organisations ... to reassure them”.⁴⁸⁵ Dr Philippa Matthews agreed.⁴⁸⁶
279. There is also a widespread need for GPs to build their confidence and competence in managing those with HIV.⁴⁸⁷ Dr Ian Williams said that many GPs felt they lacked “the confidence or skills to deliver primary care ...” for those living with HIV.⁴⁸⁸ Training is an essential part of such development, but is often poorly prioritised. For Nathaniel Ault, Chair of the National HIV Nurses Association, competing priorities for the time of GPs meant that “HIV then falls down their priority list on attending training”.⁴⁸⁹ Dr Stuart Gibson, Chair of the Faculty of Sexual Health and HIV of the British Psychological Society, noted that one HIV and psychological care training session for GPs was cancelled for three consecutive years due to low demand.⁴⁹⁰
280. Another barrier to involvement comes from poor channels of communication between primary and specialist care.⁴⁹¹ Dr Ewen Stewart felt that there were “significant pockets where communication is not good and where they [specialists] do not seem to want to let the patients go”.⁴⁹² He felt this affected skill levels. Dr Philippa Matthews believed that such practice was “probably against GMC guidance”.⁴⁹³ Sexual Health in Practice called for communication levels to be audited.⁴⁹⁴
281. There are, therefore, barriers to overcome amongst both patients and professionals. Patients must be convinced of the confidentiality of primary care through clear communication of confidentiality policies and practices.
282. For professionals, more training is required to build confidence and competence. A more knowledgeable doctor is a more confident one, and one

⁴⁸² See Q 492 (Dr Simon Barton), Q 901 (Professor Jonathan Elford), Q 284 (Dr Keith Radcliffe).

⁴⁸³ Q 717.

⁴⁸⁴ Q 717 (Dr Ewen Stewart), Q 516 (Dr Simon Barton).

⁴⁸⁵ Q 717.

⁴⁸⁶ *ibid.*

⁴⁸⁷ See Q 705 (Dr Bill Beeby), Q 287 (Dr Keith Radcliffe).

⁴⁸⁸ Q 283.

⁴⁸⁹ Q 504.

⁴⁹⁰ Q 503.

⁴⁹¹ See HAUK 31 (Ruth Hutt, Consultant in Public Health, NHS Lewisham).

⁴⁹² Q 709.

⁴⁹³ Q 704.

⁴⁹⁴ HAUK 7.

better able to take on responsibility for managing HIV. Building up confidence can also combat HIV-related stigmatisation.⁴⁹⁵

283. In addition, secondary care must acknowledge those in primary care as partners in HIV management. Not only does this enable the best delivery of primary care, for example by avoiding drug interactions, but it can also build trust between clinicians, patients and practice staff. This partnership must involve specialists highlighting to patients the levels of confidentiality in primary care and the benefits of their involvement. Partnership must also entail effective communication between services, as recommended in GMC guidance.⁴⁹⁶
284. **Upholding the confidentiality of patients is essential in any medical setting. This is particularly so for a condition as stigmatised as HIV, and in a setting as important as primary care. Confidentiality must be taken seriously, and shown to be taken seriously; general practice staff should make clear to patients the weight they attach to it. This should include clear and easily accessible confidentiality policies, and joint work with specialist HIV clinicians to highlight to patients how important confidentiality is considered within primary care.**
285. **For better, more integrated HIV treatment and care, general practices and specialist services should also work in partnership. We recommend that the Government work with professional associations to commission an audit of information-sharing processes and confidentiality policies in place between practices and HIV specialist clinics, to ensure that good practice is widespread.**
286. **Furthermore, it is imperative that medical practitioners have the knowledge and skills to manage HIV. Undergraduate teaching and ongoing professional development should, therefore, incorporate sufficient specialist training relating to HIV and AIDS.**

Going further—service networks

287. A final and more fundamental shift in services involves the development of managed service networks. These networks situate highly specialist care in ‘centres of excellence’, with satellite units taking on responsibility for less complex care. These are recommended in professionally developed treatment standards.⁴⁹⁷ The North and West Yorkshire HIV Network is one example of such a model.⁴⁹⁸
288. Such networks allow for care to be standardised through the development of care specifications and protocols throughout an area; they can also bring care closer to patients, and facilitate the involvement of primary care.⁴⁹⁹ Specialist staff we heard from in Brighton called them “best practice”⁵⁰⁰, and they were widely supported in evidence.⁵⁰¹ Nathaniel Ault, of the National HIV Nurses

⁴⁹⁵ HAUK 37 (Positively UK).

⁴⁹⁶ General Medical Council, *Good Medical Practice*, point 52:
http://www.gmc-uk.org/guidance/good_medical_practice.asp

⁴⁹⁷ British HIV Association, *Standards for HIV Clinical Care*, March 2007.

⁴⁹⁸ See Appendix 6, *op. cit.*

⁴⁹⁹ HAUK 63 (MedFASH). See also Appendix 6, *op. cit.*

⁵⁰⁰ See Appendix 4, *op. cit.*

⁵⁰¹ See, for example, HAUK 32 (St George’s Healthcare), HAUK 51 (London Specialised Commissioning Group), HAUK 63 (MedFASH), HAUK 53 (British HIV Association), HAUK 55 (British Association for Sexual Health and HIV and the Royal College of Physicians).

Association, was one of a number of contributors who called for recognition and proper funding of such models to ensure that their benefits could be felt nationwide.⁵⁰²

289. Additionally, the development of service networks could allow for the rationalisation of services in the longer-term. The Terrence Higgins Trust highlighted that there were currently 33 specialist providers in London alone, and that centres of excellence could “concentrate on highly specialist and in-patient HIV care and could be fewer in number.”⁵⁰³ NAM felt there was a “strong case for concentrating specialist care at a smaller number of major centres.”⁵⁰⁴
290. Service networks, with properly outlined pathways of care and responsibility, address a number of issues. They can deal with the issue of capacity at specialist centres. Highly specialist care could be placed into ‘centres of excellence’, allowing expert clinicians to focus on the most complex cases and develop their expertise on issues such as managing side-effects, treatment failure, drug interactions and comorbidity.⁵⁰⁵
291. Meanwhile, less complex patients could have their care delivered closer to home without compromising the quality of that care, with responsibility divided between primary care and smaller outpatient units. This supports our stated aim of increasing the involvement of primary care, and better reflects the nature of HIV as a long-term, chronic condition. It also allows for partners from the voluntary sector, along with psychological and mental health services, to be better integrated into the care pathway.
292. The proposal to commission HIV treatment and care through the national NHS Commissioning Board offers an opportunity in this respect, a point not missed by contributors to our inquiry.⁵⁰⁶ Dr Christopher Wood, though, noted that capacity may not exist nationwide for such models, and that roll-out should not be based on “atypical” examples, such as the Chelsea and Westminster hospital, where there were already strong relationships between primary care and specialist clinicians.⁵⁰⁷
293. Developing these models more widely necessitates a fundamental cultural shift in HIV care. General practice needs to become a more involved partner in caring for those living with HIV, to better establish the foundations for this model more widely. The system will also require carefully developed pathways and protocols, to ensure that patients move effectively and seamlessly between different locations for care as required.
294. Further research is essential, as is consultation with patients on how they would like the model to be structured. These are crucial first steps ahead of any wider implementation; particularly so if care is to be rationalised into a smaller number of centres. Nevertheless, we see important opportunities in a networked model of care.
295. **Commissioners should support managed service networks where they already exist. This should involve the provision of appropriate**

⁵⁰² Q 484.

⁵⁰³ HAUk 64.

⁵⁰⁴ HAUk 24.

⁵⁰⁵ Q 501 (Dr Simon Barton).

⁵⁰⁶ HAUk 55 (British Association for Sexual Health and HIV and the Royal College of Physicians), HAUk 63 (MedFASH), Q 506 (Dr Simon Barton), Q 100 (Sir Nick Partridge).

⁵⁰⁷ HAUk 44.

financial resources and the use of commissioning frameworks. Commissioners elsewhere should consider whether sufficient capacity is in place to move towards a networked model of care. NICE should consider, as part of its remit in developing treatment and care standards for HIV (see paras 247 to 248), the role of service networks as a means of efficient and integrated care provision for HIV and AIDS.

- 296. Research should be funded, either by the Government, National Institute for Health Research, Medical Research Council or other research funders, to examine whether such networks would allow for highly specialist care to be delivered more effectively in fewer centres.**
297. We have made some wide-ranging suggestions for change to better integrate care. This must include personal care to prevent further transmission of the virus. This entails help to ensure high levels of adherence, to prevent transmission and the emergence of resistance; individual behaviour interventions to reduce the risk of passing on infection; and testing and treatment for other STIs. It must also involve a broader reorganisation of services.
298. These recommendations would better orientate care in line with the long-term nature of HIV; better use the impressive expertise available within all sectors of HIV services; and improve capacity within stretched specialist services. Many of the changes can only come to fruition in the medium- to long-term, but action must begin immediately. We must be ready for major changes in how services are provided, or face insurmountable capacity pressures within a model that does not best serve its users.

CHAPTER 8: ORGANISING THE PUBLIC HEALTH RESPONSE

299. We have outlined in the previous chapter how improvements and efficiencies can be made to the commissioning and delivery of HIV treatment and care. However, given the need for a renewed focus and emphasis on prevention, it is important to consider how the public health response to HIV can be developed. The Government is undertaking a fundamental reform of the structures of public health in England. This chapter considers the effect of these reforms upon HIV prevention and testing services, and sets out how such services can be most effectively delivered.

National leadership

Public Health England

300. The Government has stated that the balance of responsibility on public health should shift from central government to local authorities and their partners.⁵⁰⁸ The intention is to transfer local health improvement functions from Primary Care Trusts to local authorities, whilst also creating a new national body, Public Health England, which will coordinate local work and manage national issues such as flu pandemics. Initial estimates from the Department of Health suggest that the total annual budget allocated to public health, across both national and local elements of delivery, will be in the order of £4 billion.⁵⁰⁹
301. HIV monitoring and surveillance is an important part of maintaining public health. Currently coordinated by the Health Protection Agency, a non-departmental public body⁵¹⁰, the importance of the HPA's monitoring systems have been repeatedly outlined in evidence we have received.⁵¹¹ In particular, we heard that systems in place to provide intelligence on the level of undiagnosed HIV are amongst the most robust of their kind in the world.⁵¹²
302. Commissioners have highlighted the central role that HPA data plays in allowing for the effective planning and delivery of treatment services.⁵¹³ Positively UK⁵¹⁴ and the Terrence Higgins Trust⁵¹⁵ asserted the importance of the independence of the HPA in allowing it the freedom to carry out surveillance programmes effectively. We recognise the success and importance of the HPA's work on HIV, and are concerned to ensure that these strengths are built upon during the process of health reform.
303. Under proposed reforms, it is envisaged that the HPA will be abolished and its work subsumed into the new national Public Health England structure. Putting public health responsibility into a single national organisation was

⁵⁰⁸ Department of Health, *Healthy Lives, Healthy People: our strategy for public health in England*, *op. cit.*

⁵⁰⁹ Q 176.

⁵¹⁰ The Cabinet Office publication, *Public Bodies 2009*, defines a non-departmental public body as a "body which has a role in the processes of national Government, but is not a Government department or part of one, and which accordingly operates to a greater or lesser extent at arm's length from Ministers."

⁵¹¹ See, for example, HAUk 55 and HAUk 57 (British Association for Sexual Health and HIV and the Royal College of Physicians), HAUk 53 (British HIV Association) and HAUk 38 (Faculty of Public Health).

⁵¹² QQ 5-6 (Professor Noel Gill, HPA).

⁵¹³ Q 762 (Justine Womack and Claire Foreman).

⁵¹⁴ HAUk 37.

⁵¹⁵ HAUk 64.

supported by a number of our witnesses, including representatives of the Faculty of Public Health and Association of Directors of Public Health.⁵¹⁶ In oral evidence, Dr Paul Cosford of the HPA supported the priority afforded to public health generally by the establishment of Public Health England; he felt that a national body with broad responsibilities provided an opportunity for better leadership of national public health initiatives.⁵¹⁷

304. Dr Cosford also highlighted that around 50% of the HPA's current income came from charitable and research sources, and that its external income-raising powers could be threatened were the functions of the HPA to be subsumed into a Government department. It was therefore suggested that Public Health England be constituted as an executive agency to preserve both the independence of monitoring and external income streams.⁵¹⁸
305. We note that, in responding to the NHS Future Forum report, the Government have stated their intention to constitute Public Health England as an executive agency, and to amend their public health reform plans accordingly.⁵¹⁹ We strongly support this development. The creation of Public Health England offers a significant opportunity for national leadership in delivering public health initiatives, and for independent advice to continue to be given to Government.
306. **The United Kingdom has an excellent system of HIV monitoring and surveillance. Monitoring has been part of the front-line response to HIV, with the HPA providing effective delivery, leadership and coordination in this respect. In undertaking reform, the Government must ensure that the surveillance of HIV infections, at a national level, continues to be appropriately resourced and managed. We recommend that Public Health England should coordinate this work nationally.**

Local delivery

307. Under proposed reforms, the majority of public health delivery responsibilities will go to local authorities, with Public Health England providing national coordination. Local authorities will take on responsibility for commissioning open-access sexual health services, providing prevention, testing and treatment for STIs. For HIV, local authorities will commission prevention and testing services, whilst treatment and care services will be commissioned nationally by the NHS Commissioning Board (see para 219).

Health and Wellbeing Boards

308. Proposed reforms envisage that local authorities will work to promote public health across their area through Health and Wellbeing Boards, which will include Directors of Public Health (see paras 318 to 323), elected representatives and representatives of adult and children's social services and NHS clinical commissioning groups. The Boards will play a key role in scrutiny and oversight of commissioning decisions. Given the split in commissioning responsibility for HIV prevention and treatment, Health and Wellbeing Boards could play an important role in the local coordination of services.⁵²⁰

⁵¹⁶ QQ 778–779.

⁵¹⁷ QQ 37–43.

⁵¹⁸ QQ 877–879.

⁵¹⁹ Department of Health, *Government changes in response to the NHS Future Forum*, 14 June 2011.

⁵²⁰ Q 789 (Simon Bowen).

309. Currently, PCTs and local authorities are required to produce a Joint Strategic Needs Assessment. This process is intended to identify existing and future health service needs to inform future service planning. The Health and Social Care Bill provides for this PCT responsibility to transfer to NHS clinical commissioning groups which, together with local authorities, will develop Joint Strategic Needs Assessments through the Health and Wellbeing Boards.
310. To meet the needs identified as part of that assessment, a duty will be placed upon clinical commissioning groups and local authorities to produce a Joint Health and Wellbeing Strategy. This is intended to coordinate delivery across NHS, social care and public health services. Both clinical commissioning groups and local councils will be under a statutory duty to have regard to the Strategy and will also have a duty to consider whether to utilise flexibilities such as pooled budgets.
311. NAT pointed out that, under current plans, there is no requirement for the national NHS Commissioning Board to be represented on local Health and Wellbeing Boards.⁵²¹ Consequently, it is unclear how HIV treatment commissioning insights will feed into local structures, given that HIV treatment is to be commissioned at the national level. This would be a significant public health omission in local authority areas such as Lambeth, where diagnosed HIV prevalence exceeds 13 cases per 1,000 people.⁵²²
312. As detailed above, NHS clinical commissioning groups and local authorities will be under a duty to 'have regard to' the Joint Health and Wellbeing Strategy when designing their commissioning plans. We would expect, particularly in areas of high prevalence, that HIV prevention and testing services would be prioritised in the Health and Wellbeing Strategy. However, it is the commissioning plans that will have most influence, given that they will directly shape the level of resources, and the nature and scope of services delivered locally.
313. A number of our witnesses have highlighted concerns regarding the extent to which commissioning plans will be influenced by Health and Wellbeing Boards, Joint Health and Wellbeing Strategies and Joint Strategic Needs Assessments. In oral evidence, Simon Bowen of the Association of Directors of Public Health said of Health and Wellbeing Boards: "It does not have any money; does not have any power ... there is no bind on the local authority or GP commissioning consortia [now NHS clinical commissioning groups] if they choose to do something different from what is set out in the Health and Wellbeing Strategy; the Health and Wellbeing Board does not have any powers to stop them."⁵²³
314. We note that, in responding to the NHS Future Forum, the Government has stated that the plans for Health and Wellbeing Boards will be amended. The Government response suggested that: "There will be a stronger expectation, set out in statutory guidance, for the (commissioning) plans to be in line with the Health and Wellbeing Strategy."⁵²⁴ Though they will not have a veto, the Boards will have a "clear right to refer plans back to the group or to the NHS

⁵²¹ HAUk 47.

⁵²² Health Protection Agency, Survey of Prevalent HIV Infections Diagnosed (SOPHID), Data tables 2009, *op. cit.*

⁵²³ Q 789.

⁵²⁴ Department of Health, *Government changes in response to the NHS Future Forum*, *op. cit.*

Commissioning Board for further consideration.”⁵²⁵ We welcome these changes, but the role of Health and Wellbeing Boards could still be strengthened further.

315. **It is essential that Health and Wellbeing Boards are able to draw upon the insights of those commissioning HIV treatment. We therefore recommend that, in areas of high HIV prevalence, the national NHS Commissioning Board be required to provide appropriate representation on local Health and Wellbeing Boards.**
316. **Health and Wellbeing Boards will be required to coordinate a wide range of public health interventions, many of which affect large numbers of people. It is possible that areas such as HIV, and sexual health more generally, may struggle to compete for attention. We therefore recommend that, in areas of high HIV prevalence, Health and Wellbeing Boards should be required to undertake an annual review of the management, coordination and integration of HIV and sexual health services.**
317. **Health and Wellbeing Boards will be particularly important for conditions such as HIV, where they provide the opportunity to coordinate disparate service commissioners and providers. We recommend that commissioners be placed under a duty to secure the approval of Health and Wellbeing Boards before finalising their commissioning plans. We also call upon the Government to make clear the funding routes and mechanisms which will ensure that Health and Wellbeing Boards can deliver their programme of work.**

Directors of Public Health

318. It is anticipated that, following the abolition of Primary Care Trusts, Directors of Public Health will become local authority employees. Directors will be the principal advocates for the health of the local population, with responsibility for leading the production of the Joint Strategic Needs Assessment and the Joint Health and Wellbeing Strategy.⁵²⁶ Appointments will be made jointly by the local authority and Public Health England. The Minister for Public Health suggested that: “Directors of Public Health are going to be critical in gathering together all the strands from the local authorities”.⁵²⁷
319. The Local Government Association and the Association of Directors of Adult Social Services welcomed the move towards local authority public health responsibility, noting that many of the major determinants of health, such as education and housing, were already administered by local government.⁵²⁸ However, the potential changes to the role, location and status of Directors of Public Health caused some alarm.
320. The Association of Directors of Public Health suggested that working within a local authority will distance Directors from GPs and the NHS.⁵²⁹ It was in fact suggested that, following reform, Directors may not be required to have public health expertise, qualifications or professional association

⁵²⁵ *ibid.*

⁵²⁶ Department of Health, *Healthy Lives, Healthy People: our strategy for public health in England*, op. cit.

⁵²⁷ Q 1134.

⁵²⁸ HAUk 69.

⁵²⁹ HAUk 36.

membership.⁵³⁰ Indeed, Dr John Middleton of the Faculty of Public Health reported a claim that some local authorities were considering appointing Directors of Leisure as Directors of Public Health.⁵³¹

321. Furthermore, whilst proposed reforms suggest that Directors will have ‘Chief Officer’ status⁵³², they do not impose any requirement for Directors to form part of the corporate management team of local authorities. This contrasts with the present position, where Directors of Public Health usually sit at a senior level in PCTs. Dr Middleton noted the importance of local authorities giving Directors of Public Health sufficient status to influence housing, environment, economic and health policies.⁵³³ Simon Bowen suggested that, should Directors not form part of the corporate management team of local authorities, there would be “very real challenges about how you influence and how you carry out that role of being the principal adviser.”⁵³⁴ The Minister for Public Health confirmed that the Government would “be reluctant to be too prescriptive” in setting out how local authorities should incorporate the role of Director of Public Health.⁵³⁵
322. Under the proposed reforms, the role of Director of Public Health will be vital in drawing together the work of public health professionals, clinical commissioning groups, adult and children’s services. They will perform a key role in guiding and steering the work of Health and Wellbeing Boards. The transfer of public health functions to local authorities offers the potential for alignment with other responsibilities, such as housing, environment and education, which can also shape health and wellbeing. However, if this is to be realised, it is essential that Directors of Public Health are in a position to shape policy in these areas. We note, with concern, that the Government response to the NHS Future Forum offers no further clarity over the role, status and work of Directors of Public Health.
323. **We recommend that Directors of Public Health should be registered with an appropriate professional body. In addition, local authorities should be required to appoint Directors of Public Health to corporate management positions. More generally, we recommend that the Department of Health should give greater formal definition to the revised role and status of Directors of Public Health.**

Public Health Outcomes Framework

324. The Government plans to establish a Public Health Outcomes Framework. The Framework, upon which consultation ended on 31 March 2011, will set out a range of outcome indicators against which local public health delivery will be measured. A ‘health premium’ will be paid to local authorities to reward successful delivery against these indicators. An indicator relating to HIV was included in the consultation’s draft set of indicators. This sought to measure the proportion of late diagnoses in a local authority area, in order to encourage local authorities to prioritise HIV testing.⁵³⁶

⁵³⁰ Q 782 (Simon Bowen).

⁵³¹ Q 784.

⁵³² HM Government, *Healthy Lives, Healthy People: Update and way forward*, July 2011.

⁵³³ Q 784.

⁵³⁴ Q 782.

⁵³⁵ Q 1138.

⁵³⁶ See Appendix 8 for definition of late diagnosis.

325. There was considerable support for the inclusion of this indicator within the final framework. The Terrence Higgins Trust believed that it would incentivise local authorities to increase testing⁵³⁷; whilst the Halve It Coalition suggested that the indicator would improve levels of early diagnosis and encourage prompt access to treatment.⁵³⁸ However, the indicator was only one of a number featuring in a draft suite of consultative indicators. The Terrence Higgins Trust stressed that the indicator must remain in the final framework.⁵³⁹
326. In addition, the Department of Health noted that the health premium will be calculated based on performance against “elements” of the framework, suggesting that not all indicators will be taken into account in the calculation of funding received under the premium.⁵⁴⁰ The HPA suggested that: “It is critical that the late diagnosis indicator proposed in the draft Public Health Outcomes Framework is adopted. This indicator will be crucial in ensuring local prevention efforts are prioritised and formally evaluated.”⁵⁴¹
- 327. The Public Health Outcomes Framework indicator on late HIV diagnosis will be vital in ensuring that HIV testing is prioritised by local authorities in the new structure. We recommend that it be included in the final adopted set of indicators by the Department of Health, and that it be included in the health premium calculation for all local authority areas.**

⁵³⁷ HAUk 64.

⁵³⁸ HAUk 50.

⁵³⁹ HAUk 64.

⁵⁴⁰ HAUk 70.

⁵⁴¹ HAUk 67.

CHAPTER 9: RECOMMENDATIONS

328. The Government should recognise the scale of the HIV and AIDS challenge in the United Kingdom. Not enough is being done to respond to a steadily growing risk to public health. There are potentially huge cost implications in both the short- and long-term in failing to deal effectively with the epidemic. At a time when public health in the United Kingdom is subject to major reform, the Government should ensure that HIV and AIDS is a key public health priority. (para 34)
329. Funding bodies, both public and private, should continue to support HIV vaccine research as part of their research strategies. Cooperation with international partners must be central to this work. At the same time, the Government should consult with the pharmaceutical sector to determine whether improvements can be made to existing models of working and regulatory processes to better involve them in efforts to develop a HIV vaccine. (para 43)
330. Although the successful development of a vaccine is crucial in the longer-term, the response to HIV and AIDS in the United Kingdom must be based on the assumption that none will exist for at least a decade. (para 44)
331. Further Government support for prevention is required. Prevention should be at the forefront of the response to HIV. This must be reflected in the Government's replacement of the 2001 sexual health strategy. More resources must be provided at national and local levels. The Government should monitor and audit the use of resources so provided, to ensure they are used for the purpose of preventing new HIV infections. (para 55)
332. We have highlighted the costs of treating HIV, and the long-term savings which could be made through investment in HIV prevention. The current levels of investment in national HIV prevention programmes are insufficient to provide the level of intervention required. (para 62)
333. Local prevention programmes, and the voluntary sector bodies that deliver them, have played an important role in tackling HIV. Local authorities, health services and other funders should avoid undermining local HIV prevention work when taking budget decisions. The ongoing trend of pressure on local prevention services also underlines the importance of enhanced Government funding for national HIV prevention programmes. (para 68)
334. HIV awareness should be incorporated into wider national sexual health campaigns, both to promote public health and to prevent stigmatisation of groups at highest risk of infection. We recommend that there should be a presumption in favour of including HIV prevention in all sexual health campaigns commissioned by the Department of Health. (para 72)
335. We accept that levels of new HIV infection would have been higher without the national prevention programmes, and we support those delivering this work. We feel, however, that more needs to be done to reduce dangerous and risky behaviour that is leading to HIV infection. In part, more funding is needed but, in addition, a broader range of evidence-based approaches are required. (para 78)
336. Both targeted and national HIV prevention campaigns have an important role to play. Given the concentration of HIV infection in two specific groups, we recommend continued targeted HIV prevention campaigning focused on

these communities. This should be coordinated at the national level. (para 84)

337. We recommend that the Department of Health undertake a new national HIV prevention campaign aimed at the general public. This will ensure that HIV prevention messages are accessible to all of the population. (para 85)
338. We recommend that those delivering HIV prevention campaigns, whether nationally or locally, should utilise the full range of available media, including internet, social networking and mobile phone applications. We note that national sexual health campaigns, such as *Sex: Worth Talking About*, have been sufficiently resourced to purchase advertising time with national broadcasters. We recommend that messages around HIV are included in these campaigns in future, ensuring the greatest possible exposure for HIV prevention messages. (para 89)
339. Whilst we do not doubt the integrity of current evaluation processes, we recommend that the practice of HIV prevention providers commissioning their own evaluation of campaigns be ended. The Department of Health should commission evaluation, ensuring separation from delivery of prevention activity. We also recommend that, once instituted, such independent evaluation activities are used to inform, refine and reinforce subsequent prevention campaigns, providing an evidence-led approach to influencing behaviour. (para 93)
340. Given the significant cost savings that can be accrued from successful HIV prevention work, the Department of Health should prioritise HIV prevention research. We recommend that the Department establish an advisory committee, to give leadership and coordination to biomedical, social and behavioural prevention research. (para 94)
341. A range of intensive interventions—including group and individual counselling work—should be delivered for those who are most at risk of either contracting or passing on HIV. This should be set against a backdrop of national campaigns and awareness-raising which is properly evaluated and refined for effectiveness. (para 97)
342. Discrimination against those affected by HIV is based, at best, on ignorance and, at worst, on prejudice, and we unreservedly condemn it. This underlines the need for a general public awareness campaign on HIV. (para 100)
343. Given the significant influence of faith leaders in some communities, we recommend that the Government, local authorities and health commissioners build upon work already taking place with all faith groups to enlist their support for the effective and truthful communication of HIV prevention messages. (para 111)
344. We recommend that the Department of Health ensures continued funding and support for work, building upon that currently delivered by the African Health Policy Network, which aims to develop the knowledge of faith leaders about HIV. Such work is vital in supporting a wider range of interventions which aim to address, prevent and treat HIV within all communities. (para 112)
345. People living with HIV need to be empowered to become advocates for understanding of the condition, in order to help to address stigma. We understand the importance of peer support networks and voluntary organisations in supporting this work, and recommend that local authorities

- and other public sector funders acknowledge the importance of this work in their future funding decisions. (para 115)
346. Progress achieved over recent decades mean that there are now many facets to HIV prevention. We recommend that the full range of available interventions be used to prevent new HIV infections. We call this approach combination prevention. (para 118)
347. We support the continued provision of needle exchange programmes. The Government should use their influence, both through partnerships such as UNAIDS and their bilateral relationships, to make clear the benefits of needle exchange facilities, and encourage countries whose epidemics are driven by injecting drug use to institute or expand such programmes. (para 125)
348. Ensuring that as many young people as possible can access good quality sex and relationships education (SRE) is crucial. We recommend that the Government's internal review of PSHE considers the issue of access to SRE as a central theme. Teaching on the biological and social aspects of HIV and AIDS should be integrated into SRE. (para 139)
349. Whilst acknowledging that the review is yet to complete its work, we recommend that the provision of SRE should be a mandatory requirement within the National Curriculum, to enable access for all. Such education should begin within all schools from Key Stage 1, though this teaching must be age-appropriate. (para 140)
350. There is an important role to be played by external providers, but we recommend that SRE should be primarily delivered by teachers, who must be trained to deliver this teaching. This training must focus on all aspects of HIV and AIDS, to ensure that teachers are confident on the subject. (para 141)
351. Procedures developed to limit the transmission of HIV from mother-to-child have been an outstanding success. We recommend that the Department of Health and commissioners ensure that such services continue to be provided as required. For the same reason, we also recommend that local authorities provide free infant formula milk to HIV-positive mothers who have no recourse to public funds. (para 146)
352. Treatment has an increasingly important role to play in preventing HIV infection. We note research demonstrating the potential for earlier antiretroviral treatment as a preventive measure. We recommend that the Department of Health, National Institute for Health Research, Medical Research Council and other research funders provide support in order to examine the utility of such approaches in the United Kingdom. In addition, the Department of Health should keep policy in this area under review as further research continues to emerge. (para 150)
353. We recommend that the Department of Health, National Institute for Health Research, Medical Research Council and other research funders support programmes of work which examine the utility of pre-exposure prophylaxis. This research should take place in both in the United Kingdom and in international settings. We recommend that the availability of post-exposure prophylaxis should continue to be determined by clinicians within GUM clinics. (para 155)
354. We recommend that the Government pursue its plans to commission offender health services centrally, which would lead to better equity and continuity of care for prisoners. (para 169)

355. Data on HIV in prisons must be improved. The Health Protection Agency should utilise surveillance data newly available to provide a robust estimate of the prevalence and profile of HIV within the prison population. At the same time, a review exercise into offender health services in public prisons is underway. The Government should supplement this with a review of the extent and nature of HIV prevention, testing and treatment services within public prisons, to determine the levels of provision across the country. (para 170)
356. We recommend that best practice for managing HIV in prisons is made clearer. The Government should commission NICE to produce guidance for the management of offender health, which should include specific protocols for HIV prevention, testing and treatment. (para 171)
357. In the meantime, the Government should draw up a guidance note to prison governors to outline best practice for managing HIV in prisons. This must stress the need for high-quality, continuous treatment and care; robust testing policies, including routine opt-out testing on entry into prison; and the provision of condoms in a confidential manner. Governors should implement these policies within their prisons as soon as possible. (para 172)
358. Earlier diagnosis ensures that those infected receive timely treatment, saving money on the treatment costs of more advanced infections and preventing onward transmission of the virus. This is cost-effective in the long-term. We therefore recommend that the Government endorse both the 2008 professional testing guidelines and the 2011 NICE testing guidelines. The policies recommended within those documents, and the recommendations made in the interim *Time to Test* report by the Health Protection Agency, should be implemented. (para 191)
359. In particular, HIV testing should be routinely offered and recommended on an opt-out basis, to newly registering patients in general practice, and to general and acute medical admissions. This should begin with high-prevalence areas (where prevalence is greater than 2 cases per 1,000 people). HIV testing should also be made routine and opt-out in relevant specialties where conditions are associated with increased rates of HIV infection, such as TB and hepatitis. Finally, testing should be expanded into the community. Local testing strategies must be put in place to facilitate this. (para 192)
360. These testing policies should be supported with financial and human resources from commissioning bodies. HIV testing should feature prominently in local needs assessments and testing strategies in high-prevalence areas. The Government must ensure that the performance of commissioners and clinicians is monitored through regularly commissioned audits now, and the late diagnosis indicator in its Public Health Outcomes Framework in future. (para 193)
361. HIV testing outside of GUM and antenatal clinics must become more widespread. Professionals, most notably general practitioners, must become more confident and competent in offering and administering tests. Training and education are important tools to use to achieve this; they should form an important part of local testing strategies. Such training must incorporate efforts to address HIV-related stigma, and develop understanding of the needs of people living with HIV. (para 204)
362. Practitioners must be more confident in identifying those at risk of HIV and those with symptoms of infection. Undergraduate training and ongoing professional development for medical practitioners should stress the

- importance of these skills. This is particularly so for specialists dealing with hepatitis and tuberculosis, where co-infection with HIV is more common. (para 205)
363. Encouraging people to test, through the provision of education, training and support, can have significant benefits for the public. We support the development of local testing strategies, recommended within NICE testing guidelines. Equipping people with the knowledge and desire to get tested should form an integral part of those strategies. (para 213)
364. The ban on HIV home testing kits, as laid out in the HIV Testing Kits and Services Regulations 1992, is unsustainable and should be repealed. A plan should be drawn up, in consultation with clinicians, patients, voluntary organisations and professional associations, to license kits for sale with appropriate quality control procedures in place. The licensing regime must make sure that the tests are accurate, and that the process gives comprehensive advice on how to access clinical and support services in order that those who test positive get the care that they need. (para 214)
365. HIV treatment and care services should be commissioned at a national level, given their high cost and the variation in HIV prevalence nationwide. To ensure commissioning is responsive to differing patterns of need across the country, regional treatment and prevention service networks, appropriately supported and resourced by the Government, should be established. (para 223)
366. Existing procurement arrangements, where antiretroviral drugs are locally procured, mean that drug prices vary across the country. This should be changed. Antiretroviral drug treatments should be procured on a national scale. This offers the potential for significant savings by making use of the purchasing power and economy of scale of the National Health Service, as well as standardising prices nationwide. (para 229)
367. The costs of HIV treatment are best managed by purchasing well-tolerated, easily adhered to drug regimens. This reduces the likelihood of incurring the much higher costs of inpatient care which result from poor adherence to treatment. Under national commissioning structures, commissioners must procure drugs that allow clinicians the flexibility to prescribe regimes that best serve this long-term view. (para 230)
368. Continued monitoring of viral resistance to drug treatments, currently carried out through the UK HIV Drug Resistance Database, is essential. (para 231)
369. We recognise the concerns arising from the proposed split in commissioning responsibility for HIV prevention, treatment and social care services. We recommend that the Department of Health place a duty upon those commissioning HIV services to support the integration of all HIV services in their commissioning decisions. (para 236)
370. We recognise the importance of prevention efforts in relation to other STIs, and the role that they can play in preventing the spread of HIV. The integration of STI and HIV treatment services, therefore, is essential for prevention efforts. We share the concerns of those who suggest that the proposed NHS reforms may increase the fragmentation of services. We recommend that the Department of Health place a duty to promote service integration upon those commissioning sexual health and HIV services. (para 237)

371. HIV treatment and care standards have an important role to play in guiding commissioners and clinicians in a complex area. We recommend that the Government commission NICE to develop treatment and care standards for HIV and AIDS. These should be developed in association with people living with and affected by HIV, along with service providers, drawing upon existing treatment guidelines. (para 247)
372. Treatment and care standards must take into account psychological and mental health needs, and social care needs more broadly. They should also reflect the value of interventions from healthcare professionals, such as advice on reducing risk behaviours, in preventing onward transmission of the virus. This should happen immediately, as the required expertise is already in place. (para 248)
373. Charging people for their HIV treatment and care is wrong for public health, practical and ethical reasons. We recommend that HIV should be added to the list of conditions in the National Health Service (Charges to Overseas Visitors) Regulations 1989, for which treatment is provided free of charge to all of those accessing care, regardless of residency status. (para 257)
374. There are a number of innovative ways of delivering specialist services which should be employed more extensively. These changes benefit patients by delivering treatment more conveniently and closer to home, whilst relieving pressure on specialist clinics and allowing closer working with those in primary care. These include:
- Home delivery of antiretroviral drugs;
 - Flexible evening and weekend access to services;
 - Patient self-management services, including more extensive support materials;
 - Virtual services such as telephone and email clinics for stable patients; and
 - Nurse-led clinics. (para 267)
375. Given the increasing proportion of HIV-positive people on stable treatment regimens, commissioners and clinicians (including GPs) should develop, after consultation with patients, guidelines and protocols for the expansion of the above innovations. This can free up human and financial resources for more complex elements of HIV treatment and care. Protocols must, however, provide for specialist consultants to monitor the conditions of all patients at regular intervals. (para 268)
376. We recommend that the Government work with specialists, GPs and patients to develop a strategy for GPs to take on shared responsibility for the care of HIV-positive patients. This work should include broader consideration of the appropriate boundaries of responsibility between primary care and specialist services. The results should form the basis of longer-term strategies for expanding the role of GPs in the management of HIV-positive patients. (para 277)
377. Upholding the confidentiality of patients is essential in any medical setting. This is particularly so for a condition as stigmatised as HIV, and in a setting as important as primary care. Confidentiality must be taken seriously, and shown to be taken seriously; general practice staff should make clear to patients the weight they attach to it. This should include clear and easily accessible confidentiality policies, and joint work with specialist HIV clinicians to highlight to patients how important confidentiality is considered within primary care. (para 284)

378. For better, more integrated HIV treatment and care, general practices and specialist services should work in partnership. We recommend that the Government work with professional associations to commission an audit of information-sharing processes and confidentiality policies in place between practices and HIV specialist clinics, to ensure that good practice is widespread. (para 285)
379. It is imperative that medical practitioners have the knowledge and skills to manage HIV. Undergraduate teaching and ongoing professional development should, therefore, incorporate sufficient specialist training relating to HIV and AIDS. (para 286)
380. Commissioners should support managed service networks where they already exist. This should involve the provision of appropriate financial resources and the use of commissioning frameworks. Commissioners elsewhere should consider whether sufficient capacity is in place to move towards a networked model of care. NICE should consider, as part of its remit in developing treatment and care standards for HIV, the role of service networks as a means of efficient and integrated care provision for HIV and AIDS. (para 295)
381. Research should be funded, either by the Government, National Institute for Health Research⁵⁴², Medical Research Council or other research funders, to examine whether service networks would allow for highly specialist care to be delivered more effectively in fewer centres. (para 296)
382. The United Kingdom has an excellent system of HIV monitoring and surveillance. Monitoring has been part of the front-line response to HIV, with the HPA providing effective delivery, leadership and coordination in this respect. In undertaking reform, the Government must ensure that the surveillance of HIV infections, at a national level, continues to be appropriately resourced and managed. We recommend that Public Health England should coordinate this work nationally. (para 306)
383. It is essential that Health and Wellbeing Boards are able to draw upon the insights of those commissioning HIV treatment. We therefore recommend that, in areas of high HIV prevalence, the national NHS Commissioning Board be required to provide appropriate representation on local Health and Wellbeing Boards. (para 315)
384. Health and Wellbeing Boards will be required to coordinate a wide range of public health interventions, many of which affect large numbers of people. It is possible that areas such as HIV, and sexual health more generally, may struggle to compete for attention. We therefore recommend that, in areas of high HIV prevalence, Health and Wellbeing Boards should be required to undertake an annual review of the management, coordination and integration of HIV and sexual health services. (para 316)
385. Health and Wellbeing Boards will be particularly important for conditions such as HIV, where they provide the opportunity to coordinate disparate service commissioners and providers. We recommend that commissioners be placed under a duty to secure the approval of Health and Wellbeing Boards before finalising their commissioning plans. We also call upon the Government to make clear the funding routes and mechanisms which will ensure that Health and Wellbeing Boards can deliver their programme of work. (para 317)

⁵⁴² An NHS-led research institute, which commissions and funds research.

386. We recommend that Directors of Public Health should be registered with an appropriate professional body. In addition, local authorities should be required to appoint Directors of Public Health to corporate management positions. More generally, we recommend that the Department of Health should give greater formal definition to the revised role and status of Directors of Public Health. (para 323)
387. The Public Health Outcomes Framework indicator on late HIV diagnosis will be vital in ensuring that HIV testing is prioritised by local authorities in the new structure. We recommend that it be included in the final adopted set of indicators by the Department of Health, and that it be included in the health premium calculation for all local authority areas. (para 327)

APPENDIX 1: MEMBERS AND DECLARATIONS OF INTEREST

Members

The Members of the Committee which conducted this inquiry were:

Lord Fowler (Chairman)
 Lord Gardiner of Kimble
 Baroness Gould of Potternewton
 Baroness Healy of Primrose Hill
 Baroness Hussein-Ece
 Lord McColl of Dulwich
 Baroness McIntosh of Hudnall
 Baroness Masham of Ilton
 Lord May of Oxford
 Lord Rea
 Baroness Ritchie of Brompton
 Baroness Tonge

Specialist Adviser

Professor Anne Johnson, Co-Director, Institute of Global Health, University College London.

Declared Interests

The following relevant interests were declared:

Lord Fowler (Chairman)

Honorary Life Fellow, British Association for Sexual Health and HIV
Former trustee, Terrence Higgins Trust (HIV third sector organisation)
Former Vice-Chair, All-Party Parliamentary Group on HIV and AIDS
Former Secretary of State for Social Services 1981–1987

Lord Gardiner of Kimble

None

Baroness Gould of Potternewton

Former Chair, Independent Advisory Group on Sexual Health and HIV (government sponsored body) (honorarium)
Patron, Yorkshire MESMAC (sexual health information & resources for Gay men in the North of England)
Patron, HIV Sport
Patron, Sussex Beacon
Member, All-Party Parliamentary Group on HIV and AIDS
Honorary Life Fellow, British Association for Sexual Health and HIV
Member, Halve it (campaign aimed at halving the number of those living with undiagnosed HIV)
Honorary Fellow, Faculty of Sexual and Reproductive Health
Chair, All-Party Parliamentary Group for Sexual and Reproductive Health in the UK
President, Family Planning Association
Co-Chair of the Department of Health Sexual Health Forum

Baroness Healy of Primrose Hill

None

Baroness Hussein-Ece

None

Lord McColl of Dulwich

Former President, Mildmay Mission Hospital, Hackney.

Baroness McIntosh of Hudnall

Member of a General Medical Council working group preparing new guidance for doctors involved in child protection.

Baroness Masham of Ilton

Former Board Member, London Lighthouse (HIV and AIDS treatment centre)

Vice-Chair, All-Party Parliamentary Group on HIV and AIDS

Vice President, Mildmay Mission Hospital, Hackney (HIV rehabilitation, respite and hospice care)

Member, All-Party Parliamentary Group on Prison Health

Vice-Chair, All-Party Parliamentary Group on Drug Misuse

Lord May of Oxford

(Past) interests as academic researcher on epidemiology of HIV/AIDS

Lord Rea

Former NHS General Practitioner and Lecturer in Social Medicine

Chairman, Associate Parliamentary Food and Health Group

Trustee, National Heart Forum

Baroness Ritchie of Brompton

Portfolio Holder, Family and Children's Services, Royal Borough of Kensington and Chelsea

President, National Children's Bureau (host of the Sex Education Forum)

Baroness Tonge

NHS General Practitioner and Family Planning doctor, 1964–1997

Manager, Women's Health Services, Ealing Health Authority, 1982–1987

Honorary Fellow, Faculty of Sexual and Reproductive Health, Royal College of Obstetricians and Gynaecologists

Past Officer, All Party Parliamentary Group on HIV and AIDS

Chair, All Party Parliamentary Group on Population, Development and Reproductive Health

Liberal Democrat Spokesperson for International Development, 1997–2003 (Commons)

Liberal Democrat Spokesperson for Health, 2007–2010 (Lords)

A full list of Members' interests can be found in the Register of Lords Interests:
<http://www.publications.parliament.uk/pa/ld/ldreg.htm>

Professor Anne Johnson (Specialist Adviser)

Employment:

University College London

Honorary appointments:

Honorary Consultant in Public Health Medicine, Camden Primary Care Trust

Honorary Consultant in Public Health Medicine, Royal Free Hospital NHS Trust

Visiting Professor, London School of Hygiene and Tropical Medicine

Governorship:

Governor of the Wellcome Trust

Member:

British Association for Sexual Health and HIV (BASHH)

Research Grant Funding

My programme of research in the field of HIV, Sexual Health and Flu funded by Wellcome Trust, Medical Research Council, Department of Health, National Institute for Health Research.

My research in observational studies of Hepatitis B funded by Nuffield, with additional grants from Novartis, Bristol Myers Squibb and Gilead Sciences.

Family:

Spouse is an employee of the Health Protection Agency

APPENDIX 2: LIST OF WITNESSES

Evidence

Evidence is published online at <http://www.parliament.uk/hivselect> and available for inspection at the Parliamentary Archives (020 7219 5314)

Evidence received by the Committee is listed below in order of receipt and in alphabetical order. Witnesses without a * gave written evidence only. Witnesses marked with * gave both oral and written evidence. Witnesses marked with ** gave oral evidence and did not submit any written evidence.

Oral evidence in chronological order

- | | | |
|----|--------------|---|
| * | (QQ 1–75) | Health Protection Agency |
| * | (QQ 76–137) | Terrence Higgins Trust, African Health Policy Network, NAM |
| * | (QQ 138–229) | Department of Health |
| * | (QQ 230–307) | British HIV Association (BHIVA), British Association for Sexual Health and HIV (BASHH) and Royal College of Physicians, Medical Foundation for AIDS & Sexual Health (MedFASH) |
| ** | (QQ 308–348) | National Institute for Health and Clinical Excellence (NICE) |
| * | (QQ 349–386) | Mr John Nawrockyi, Association of Directors of Adult Social Services (ADASS), Mr Paul Elfick, Senior Specialist Social Worker, Adults and Family Wellbeing, Buckinghamshire County Council, and Mr Andrew Pearmain, HIV Consultant Practitioner, Essex County Council |
| * | (QQ 387–429) | International AIDS Vaccine Initiative (IAVI), ViiV Healthcare, Gilead Sciences |
| * | (QQ 430–477) | Professor Sir Andrew McMichael, Weatherall Institute of Molecular Medicine, Oxford University, Professor Jonathan Weber, Imperial College, London, Dr Sheena McCormack, Medical Research Council Clinical Trials Unit |
| * | (QQ 478–536) | Dr Simon Barton, Chelsea and Westminster Hospital, British Psychological Society, National HIV Nurses Association (NHIVNA), HIV Pharmacy Association (HIVPA) |
| * | (QQ 537–588) | Positive East, Body & Soul, Positively UK |
| * | (QQ 589–638) | Sex Education Forum, Brook, Family Planning Association (FPA), Personal, Social, Health and Economic Education (PSHE) Association |
| ** | (QQ 639–670) | Muslim Council of Britain, Church of England, Catholic Church, Reverend Ijeoma Ajibade, St Philips Earls Court, Church of England |
| * | (QQ 671–722) | Royal College of General Practitioners, Sex, Drugs and HIV Group, Sexual Health In Practice (SHIP), Birmingham, British Medical Association |

- * (QQ 723–766) NHS South West, Office for Sexual Health South West, London Specialised Commissioning Group
- * (QQ 767–832) NHS Brent, NHS Lambeth, Faculty of Public Health
- * (QQ 833–879) Health Protection Agency
- * (QQ 880–912) Professor Graham Hart, University College London, Professor Jonathan Elford, City University, Mr Peter Weatherburn, London School of Hygiene and Tropical Medicine, and Director, Sigma Research
- ** (QQ 913–1012) Central Office of Information (COI), National Social Marketing Centre, Ms Kate Waters
- ** (QQ 1013–1088) Nick Gibb MP, Minister of State for Schools, Department for Education
- * (QQ 1089–1140) Anne Milton MP, Parliamentary Under-Secretary of State for Public Health, Department of Health

Written evidence in order of receipt

- (HAUK 1) Mr Sascha Auweiler
- (HAUK 2) Mr Kevin Kellerher
- (HAUK 3) Naz Project London
- (HAUK 4) Shika Tamaa Support Services (STaSS)
- * (HAUK 5) Family Planning Association (FPA)
- (HAUK 6) North East London HIV and Sexual Health Clinical Network (NELNET)
- * (HAUK 7) Sexual Health In Practice (SHIP) Birmingham
- * (HAUK 8) Professor Graham Hart
- * (HAUK 9) Public Health, NHS Lambeth and Sexual Health Commissioning, LSL Alliance
- (HAUK 10) The Children's HIV Association (CHIVA) for the UK and Ireland
- (HAUK 11) Mildmay UK
- * (HAUK 12) Sexual Health/HIV Faculty, Division of Clinical Psychology, British Psychological Society
- (HAUK 13) Mr David Bridle, Boyz Magazine
- * (HAUK 14) Professor Sir Andrew McMichael
- (HAUK 15) City Healthcare Partnership, Hull
- (HAUK 16) Time2Know Partnership
- (HAUK 17) Sima Chaudhury
- (HAUK 18) The Brunswick Centre
- * (HAUK 19) Department of Health
- (HAUK 20) Dr Sris Allan
- (HAUK 21) The Metro Centre Ltd
- * (HAUK 22) Body & Soul
- (HAUK 23) LASS
- * (HAUK 24) NAM
- (HAUK 25) Dr T R Moss and Mrs A J Woodland
- (HAUK 26) Shield South Yorkshire HIV Support Group

- * (HAUK 27) Sigma Research and Department for Social and Environmental Health Research (SEHR), London School of Hygiene and Tropical Medicine
- (HAUK 28) Wellcome Trust
- * (HAUK 29) Professor Jonathan Elford
- (HAUK 30) National Study of HIV in Pregnancy and Childhood (NSHPC)
- (HAUK 31) NHS Lewisham
- (HAUK 32) St George's Healthcare
- (HAUK 33) Status
- (HAUK 34) Dr Mario Cortina-Borja
- (HAUK 35) Royal College of Nursing
- (HAUK 36) Association of Directors of Public Health (UK)
- * (HAUK 37) Positively UK
- * (HAUK 38) Faculty of Public Health of the Royal Colleges of Physicians of the United Kingdom
- (HAUK 39) Kevin Kelleher
- (HAUK 40) Rehabilitation and HIV Association
- (HAUK 41) Association of British Insurers
- (HAUK 42) Haemophilia Society
- (HAUK 43) Tcell
- (HAUK 44) Dr Christopher Wood
- (HAUK 45) Tuke Institute
- * (HAUK 46) Brook
- (HAUK 47) National AIDS Trust
- * (HAUK 48) HIV Pharmacy Association
- * (HAUK 49) Sex Education Forum
- (HAUK 50) Halve It Coalition
- * (HAUK 51) London Specialised Commissioning Group
- * (HAUK 52) National HIV Nurses Association (NHIVNA)
- * (HAUK 53) British HIV Association (BHIVA)
- * (HAUK 54) Royal College of General Practitioners Sex, Drugs and HIV Group
- * (HAUK 55) British Association for Sexual Health and HIV (BASHH) and Joint Specialty Committee (JSC) for Genitourinary Medicine, Royal College of Physicians (RCP)
- * (HAUK 56) Dr Sheena McCormack: Senior Clinical Scientist, Medical Research Council Clinical Trials Unit; Reader in Clinical Epidemiology, Imperial College; Consultant HIV/GU Physician, Chelsea & Westminster NHS Foundation Trust
- * (HAUK 57) African Health Policy Network
- (HAUK 58) Medical Research Council

(HAUK 59)	National African HIV Prevention (NAHIP) Programme
(HAUK 60)	South West London HIV and Sexual Health Network, SWAGNET
(HAUK 61)	HIV Scotland
(HAUK 62)	Scottish Government
★ (HAUK 63)	Medical Foundation for AIDS & Sexual Health MedFASH
★ (HAUK 64)	Terrence Higgins Trust
★ (HAUK 65)	International AIDS Vaccine Initiative (IAVI)
★ (HAUK 66)	MedFASH
★ (HAUK 67)	Health Protection Agency
★ (HAUK 68)	Health Protection Agency (supplementary)
★ (HAUK 69)	Local Government Association and Association of Directors of Adult Social Care
★ (HAUK 70)	Department of Health (supplementary)
★ (HAUK 71)	Professor Jonathan Weber
(HAUK 72)	Professor Virginia Berridge
★ (HAUK 73)	British Association for Sexual Health and HIV (BASHH) and Joint Specialty Committee (JSC) for Genitourinary Medicine, Royal College of Physicians (RCP) (supplementary)
★ (HAUK 74)	Gilead Sciences Ltd
(HAUK 75)	International Partnership for Microbicides
★ (HAUK 76)	British Medical Association (BMA)
★ (HAUK 77)	HIV Pharmacy Association (HIVPA) (supplementary)
(HAUK 78)	Summit House Support Ltd, Paul Sheenan, PCT Sexual Health Commissioner and Diane McNulty, PCT Sexual Health Commissioner
★ (HAUK 79)	Positively UK (supplementary)
(HAUK 80)	UK-CAB UK-Community Advisory Board
(HAUK 81)	African Health Forum
(HAUK 82)	Greater Manchester Sexual Health Network
★ (HAUK 83)	Family Planning Association (FPA)
(HAUK 84)	Felton Communications
★ (HAUK 85)	NHS South West, Office for Sexual Health in the South West
★ (HAUK 86)	Personal, Social, Health and Economic Education (PSHE) Association
★ (HAUK 87)	Body & Soul (supplementary)
★ (HAUK 88)	National HIV Nurses Association (supplementary)
(HAUK 89)	International Centre for Prison Studies
★ (HAUK 90)	Faculty for HIV & Sexual Health, British Psychological Society (supplementary)
★ (HAUK 91)	Sex Education Forum (supplementary)
(HAUK 92)	Department of Health's Offender Health Unit
(HAUK 93)	Edinburgh Drug and Alcohol Partnership

- * (HAUK 94) Department of Health (further supplementary)
- (HAUK 95) Ministry of Defence
- (HAUK 96) UK Border Agency
- * (HAUK 97) Health Protection Agency (further supplementary)
- * (HAUK 98) Terrence Higgins Trust (supplementary)
- (HAUK 99) Bristol-Myers Squibb
- * (HAUK 100) NHS South West, Office for Sexual Health in the South West (supplementary)
- * (HAUK 101) London Specialised Commissioning Group (supplementary)
- (HAUK 102) National African HIV Prevention Programme (NAHIP) (supplementary)
- (HAUK 103) Greater Manchester Sexual Health Network and NHS Manchester (supplementary)
- (HAUK 104) All Party Parliamentary Group on HIV and AIDS
- * (HAUK 105) British Medical Association, General Practitioners Committee (supplementary)
- (HAUK 106) Department of Health (further supplementary)
- (HAUK 107) Health Protection Agency (further supplementary)
- (HAUK 108) Mildmay UK (supplementary)

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- ** Reverend Ijeoma Ajibade
- All Party Parliamentary Group on HIV and AIDS (HAUK 104)
- Dr Sris Allan (HAUK 20)
- Association of British Insurers (HAUK 41)
- * Association of Directors of Adult Social Care and the Local Government Association (HAUK 69)
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- Mr Sascha Auweiler (HAUK 1)
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- * British Medical Association (HAUK 76, 105)
- * Sexual Health/HIV Faculty of the British Psychological Society (HAUK 12, 90)
- * Brook (HAUK 46)

- The Brunswick Centre (HAUK 18)
- ★★ Anscombe Bioethics Centre, Catholic Church
- Sima Chaudhury (HAUK 17)
- The Children's HIV Association (CHIVA) for the UK and Ireland (HAUK 10)
- City Healthcare Partnership Hull (HAUK 15)
- ★★ Central Office of Information (COI)
- ★★ The Archbishop's Council, Church of England
- Dr Mario Cortina-Borja ((HAUK 34)
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- ★★ Mr Paul Elfick
- * Professor Jonathan Elford (HAUK 29)
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- International Centre for Prison Studies (ICPS) (HAUK 89)
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- Mr Kevin Kelleher (HAUK 2, 39)
- LASS (HAUK 23)
- * London Specialised Commissioning Group (HAUK 51, 101)
- * Dr Sheena McCormack: Senior Clinical Scientist, Medical Research Council Clinical Trials Unit; Reader in Clinical Epidemiology, Imperial College; Consultant HIV/GU Physician, Chelsea & Westminster NHS Foundation Trust (HAUK 56)
- * Professor Sir Andrew McMichael (HAUK 14)
- * Medical Foundation for AIDS & Sexual Health (MedFASH) (HAUK 63, 66)
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- Mildmay UK (HAUK 11, 108)
- Dr T R Moss and Mrs A J Woodland (HAUK 25)
- ★★ Muslim Council of Britain

- ★ NAM (HAUK 24)
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- ★ National HIV Nurses Association (NHIVNA) (HAUK 52, 88)
- ★★ National Institute for Health and Clinical Excellence (NICE)
- ★★ National Social Marketing Centre
National Study of HIV in Pregnancy and Childhood (NSHPC) (HAUK 30)
Naz Project London (HAUK 3)
North East London HIV and Sexual Health Clinical Network (NELNET) (HAUK 6)
- ★★ Mr Andrew Pearmain
- ★ Personal, Social, Health and Economic Education (PSHE) Association (HAUK 86)
- ★★ Positive East
- ★ Positively UK (HAUK 37, HAUK 79)
- ★ Public Health, NHS Lambeth and Sexual Health Commissioning, LSL Alliance (HAUK 9)
NHS Lewisham (HAUK 31)
Rehabilitation and HIV Association (HAUK 40)
- ★ Royal College of General Practitioners Sex, Drugs and HIV Group (HAUK 54)
Royal College of Nursing (HAUK 35)
St George's Healthcare Trust (HAUK 32)
Scottish Government (HAUK 62)
- ★ Sex Education Forum (HAUK 49, 91)
- ★ Sexual Health In Practice (SHIP) Birmingham (HAUK 7)
Shield South Yorkshire HIV Support Group (HAUK 26)
Shika Tamaa Support Services (STaSS), Milton Keynes (HAUK 4)
- ★ Sigma Research and Department for Social and Environmental Health Research (SEHR), London School of Hygiene and Tropical Medicine (HAUK 27)
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- ★ NHS South West, Office for Sexual Health in the South West (HAUK 85, 100)
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Tcell (HAUK 43)
- ★ Terrence Higgins Trust (HAUK 64, 98)
Time2Know Partnership (HAUK 16)
Tuke Institute (HAUK 45)
UK Border Agency (HAUK 96)
UK-Community Advisory Board (HAUK 80)
- ★★ ViiV Healthcare

- ★★ Ms Kate Waters
- ★ Professor Jonathan Weber (HAUK 71)
Wellcome Trust (HAUK 28)
Dr Chris Wood (HAUK 44)

APPENDIX 3: CALL FOR EVIDENCE

The House of Lords has established a Select Committee on HIV and AIDS in the United Kingdom. The orders of reference of the inquiry are: “that a Select Committee be appointed to consider HIV and AIDS in the United Kingdom”.

The Committee in particular will explore the following key issues in detail and would welcome your views on **any or all** of the following questions. **Please note that questions are not listed here in any particular order of importance.**

Written evidence should arrive no later than Friday 18th February 2011.

Monitoring

- (a) How robust is the current system for monitoring the number of people with HIV in the United Kingdom?
- (b) Will the proposed public health reforms impact on this system?
- (c) Could anything be done to improve monitoring?
- (d) What groups in particular are at risk from HIV?

Prevention

- (a) Is Government policy sufficiently focused on HIV prevention?
- (b) Have the right groups been targeted in recent prevention campaigns?
- (c) To what extent have prevention initiatives targeted at injecting drug users been successful?
- (d) How could prevention initiatives be better delivered and evaluated?

Testing

- (a) Are current testing policies adequate across the country?
- (b) What can be done to increase take-up rates?

Treatment

- (a) How can the NHS best commission and deliver HIV treatment?
- (b) What impact might the proposed new commissioning reforms have on HIV treatment?
- (c) In what setting can treatment most effectively be delivered?

Cost

- (a) Have cost considerations been satisfactorily balanced with public health imperatives in HIV:
 - (i) prevention policy; and
 - (ii) treatment policy?
- (b) Is research funding correctly prioritised?

Stigma

- (a) What impact does stigmatisation of those with HIV have on those infected, and on addressing HIV as a public health problem?
- (b) Where are problems of stigmatisation most acute?
- (c) What measures are currently taken to tackle HIV stigmatisation? What more should be done?

APPENDIX 4: VISIT TO BRIGHTON 15 MARCH 2011

The Committee visited the Royal Sussex County Hospital, the Sussex Beacon and St Peter's Medical Practice in Brighton.

Lord Fowler, Lord Gardiner of Kimble, Baroness Gould of Potternewton, Baroness Healy of Primrose Hill, Baroness Masham of Ilton, Lord Rea and Professor Anne Johnson (Specialist Adviser) were in attendance.

Royal Sussex County Hospital

The Committee visited the Royal Sussex County Hospital, part of the Brighton and Sussex University Hospitals Trust. The visit began with a presentation on services in Brighton by staff at the hospital. The Committee was then given a tour of facilities at the Royal Sussex County Hospital. Finally, the Committee was addressed by Duncan Selbie, Chief Executive of the Brighton and Sussex University Hospital Trust.

The Committee would like to thank the following personnel from the hospital for their work in arranging activities on the day, and for their time in providing information to the Committee:

- Dr Martin Fisher, Consultant/Research director
- Venessa Neylen, Clinical services manager, HIV/GUM service
- Dr Daniel Richardson, Consultant manager
- Dr Duncan Churchill, Consultant/Deputy chief of safety
- Dr Yvonne Gilleece, Consultant
- Dr Suneeta Soni, Consultant
- Dr Gillian Dean, Consultant
- Dr Debbie Williams, Consultant
- Dr Laura Waters, Locum consultant
- Gary Seaton, HIV clinical nurse specialist
- Heather Leake-Date, Consultant pharmacist
- Leigh Harvey, HIV/GUM matron
- Alan Phillips, Senior sexual health nurse
- Tracy Buckingham, Senior HIV outpatient nurse
- Guido Tapia, Senior HIV inpatient nurse
- Andy Parkhouse, Senior health adviser
- Emma Collins, Sexual health practice development nurse
- Catherine Hendricx, HIV/GUM patient access manager
- Jonathan Roberts, Liaison health adviser

Multidisciplinary team presentation

Patient profile

Prevalence

Diagnosed HIV prevalence in Brighton was the eighth highest for any Primary Care Trust in the country, with 7.57 people per 1000 of population diagnosed with HIV.

Infection route

Approximately 80% of patients were infected with HIV through sex between men, and 17.5% through heterosexual sex. There was a disparity in levels of late diagnosis between heterosexual and homosexual cases: men who had sex with men were diagnosed late in 30% of cases; 60% of heterosexual patients were diagnosed late.

10% of the population in Brighton were men who have sex with men (MSM). One study estimated that HIV prevalence (including both those diagnosed and undiagnosed) amongst MSM was as high as 13.7%. Another study found that around 40% of men attending gay venues was infected with HIV, with one-third of those undiagnosed. Data from a third study indicated that around 50% of MSM reported unprotected sex in the previous twelve months, a figure which was higher amongst HIV-positive MSM.

Ethnicity

Around 85% of patients were white; 11% were black African, with small numbers of patients from other ethnic groups.

Age

Approximately one-third of patients were over 50, and around 15% of new diagnoses were of people aged over 50.

Patient pathway

Most patients were diagnosed in GUM services, during treatment for opportunistic infections or during routine testing.

After diagnosis, the multidisciplinary team met to discuss new patients. Subsequently, there were weekly meetings, where patient plans were drawn up and early progress monitored. This approach was designed to ensure consistent patient management.

Subsequently, there was a fixed programme with set treatment intervals; intervals could be extended depending on patient stability. This was facilitated by the *CONNECT* service, which allowed for results to be emailed, reducing time spent in hospital where appropriate.

Patient issues

General

The problems experienced by patients in dealing with their infection were manifold. Psychosocial issues, problems with adherence and sexual health and difficulties in primary care settings were all common. Monitoring, observation and collaboration with GPs were important in long-term patient management.

HIV-related dementia was an emerging issue as the cohort aged. Antiretrovirals were very effective at preventing dementia, but it remained of concern. The Sussex Beacon was considering dementia as part of its strategy for the future.

Treatment burden

The daily routine and burdens of treatment were lifelong, a fact which could lead to psychological problems; depression and anxiety were possible side-effects of treatment, a notion which it was important to investigate.

Treatment side-effects ranged from gastrointestinal and kidney problems to increased cholesterol levels; such problems could be monitored and addressed, but

affected the tolerability of treatment. Sometimes symptoms were attributed to antiretrovirals by patients.

Stigma

Stigma often concerned prosaic issues—travel, insurance, the workplace. It persisted in minority communities; including within the gay community, where HIV sometimes invoked negative perceptions.

Co-infections

Modelling had shown that co-infections, such as syphilis, were linked with increases in infectivity levels of as much as 10 times. The Brighton Community HIV team had given intense focus to syphilis testing and partner notification, but 150 cases a year were still observed.

Another virus, *Lymphogranuloma Venereum*, was observed in MSM in 2005, but after intense testing and surveillance, in collaboration with the Health Protection Agency, case numbers had decreased to between 2 and 10 cases per year.

Hepatitis C cases were also a problem within the Brighton cohort, predominantly amongst MSM: there were 10–15 cases a year among HIV-positive patients.

Primary care

Primary care was an important element of HIV management. The default position was to keep GPs informed on patient progress where there was consent; particularly so if conditions changed, to avoid drug conflicts. For those who did not want GP involvement, engagement was encouraged but could not be mandated.

To ensure greater GP involvement, a local enhanced GP network had been established (see paras 90–91). This involved training and accreditation of participating practices by the Primary Care Trust (PCT). Payments were then made for each HIV patient in the practice whose primary care needs—such as vaccinations and management of cardiovascular risk—were addressed. This was not HIV management; it was primary care for those with HIV.

Such contracts had encouraged patient disclosure to GPs—St Peter's, for example, had 120 HIV-positive patients. The annual training course was being sent out to other areas as an example of good practice.

Testing

Overview

A study had looked at previous cases of those with HIV diagnosed following opportunistic infections: it showed that in 60% of cases, there were opportunities to test earlier that were missed; and for primary HIV infection, opportunities were missed in 50% of cases. The statistics highlighted the importance of promoting testing.

Barriers

The team were asked about the main barriers to HIV testing. There were three main barriers: people living with HIV themselves; the healthcare environment; and wider societal aspects.

One major barrier was the fact that it was not normalised for the demographics most at risk to test frequently. This was being addressed: in previous studies, only 50% of MSM had ever been HIV tested; now, data in London indicated that

around 50% of MSM had been tested within the last 12 months. The team had worked hard to improve the frequency of sexual health screens for HIV-positive patients. Amongst MSM, those screening yearly had increased markedly: offer and acceptance rates rose from 40% to offer rates approaching 100%, and acceptance rates of nearly 70%. This was possibly reflective of a culture shift, but stigma—over issues such as confidentiality—remained a major problem.

Another important barrier related to the reticence of healthcare professionals. There were a number of refrains common to hospital doctors, GPs and practice nurses: that there was insufficient time; that they were insufficiently trained; or that testing was unrelated to their role. The challenge therefore was in boosting offer rates; acceptance rates tended to be high. Research suggested that professionals were more likely to offer tests to younger people, despite the ageing cohort; and younger professionals were more likely to offer tests.

Consent

There was a false perception that gaining informed consent was a “lengthy process”; in fact, the average consent consultation lasted less than a minute, and was often significantly quicker. Antenatal testing had shown that obtaining consent was not a time barrier; education and training overcame initial hesitation by midwives, and acceptance rates were now very high.

The Committee queried whether consent was necessary for HIV testing. The Brighton team noted that GMC guidelines required clinicians to inform patients before testing, and to offer the right to refuse. These requirements were, however, the same for all HIV testing, including during antenatal screening; success there had shown that the requirements were not necessarily a barrier to testing.

Testing research

In 2009 Brighton and Hove were awarded two Department of Health grants for testing pilots. One involved encouraging GPs to offer HIV tests to all new registrants: there were 800 tests offered in 6 months, with uptake rates ranging from 36% to 75%. The other was focused on acute admissions to the Royal Sussex hospital: the offer rate was around 40%, with a very high uptake rate of 91%.

These results led to the adoption of acute admissions testing as a CQUIN⁵⁴³ funding point. Offer and uptake rate targets were set at 60% and 80% respectively; targets that were being met up to the end of February 2011.

Home testing

Home testing was currently illegal, but people were ordering tests online regardless. A study into home sampling had shown an acceptance rate above 70%, but home testing was very different. The problem was that referral pathways were not pronounced, an area of concern.

Treatment

Overview

Nationally, between 90 and 92% of patients had undetectable viral loads; at Brighton, this was above 96%. This success related to high adherence rates, ensured through the work of the multidisciplinary adherence team. Treatment

⁵⁴³ Commissioning for Quality and Innovation payment framework:

http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_091443

failure was rare; where it did occur, there were management plans in place to address issues of adherence, toxicity or tolerability.

Specialisation

Prescription of drugs remained with specialists. Research had shown that this was a sound distinction: GPs felt that they lacked the necessary skill; patients did not have sufficient confidence in antiretroviral prescription by non-specialists. Regardless of NHS reform, this was unlikely to change. There were clear benefits to the approach: clinicians found it useful to have peer support when devising a regime, and it was helpful to have a multidisciplinary team in place to monitor progress.

Innovations

The centre had developed a number of innovations in the delivery of treatment. There was a home delivery service for antiretroviral drugs; used by 79% of patients on antiretroviral drugs, it saved around £60,000 per month in VAT payments.

The *CONNECT* service emailed blood results to consenting patients, reducing the number of visits required by stable patients. 350 patients received results using the service, with their confidentiality protected. This meant only one visit to hospital in a year for a stable patient, which freed up resources to attend to more complex patients.

Treatment and prevention

The question of treating all those infected, regardless of CD4 count, was raised. It was a model that had been adopted in San Francisco, but its adoption would require a “mind shift”, as treatment would for the first time be geared towards the benefit of public, rather than individual, health; and ensuring adherence in such circumstances could prove to be difficult. Regardless, it was necessary to gather data in randomised trials before there could be any progress.

This approach perhaps missed the point; the bigger problem was reducing the fraction of those with HIV who were undiagnosed. This required more intensive testing strategies, and efforts to reduce onward transmission.

Prevention

Patients were most infectious in the first few months following infection, and evidence suggested that undiagnosed or very recently diagnosed HIV-positive individuals transmitted HIV more than any other groups. Education, health promotion and earlier diagnoses were thus important for the benefit of both public and individual health.

Prevention messages were important; but there was a balance to strike between showing that treatment was a burden and encouraging people to get tested, as highlighting the benefits of treatment was a powerful message in engaging chaotic patients.

Migrant charging

For migrants not eligible for free NHS care, only HIV tests and pre-test counselling were available without charge. This was not as pronounced an issue in Brighton owing to the low numbers of ethnic minority patients, but it was a possible issue on the peripheries of the catchment area.

Charging regulations put doctors in a difficult position: treating HIV was in the public interest, and their core role did not involve law enforcement. Furthermore,

patient circumstances meant it was often difficult to assess eligibility; and if mistakes were made, subsequent engagement of patients would be difficult.

Prisons

The Brighton and Sussex University Hospitals Trust were not involved in prison sexual health services. When they were, it was often difficult for patients to access services, but information suggested that this was no longer the case. However, sexual health screening was still not as systematic as in some parts of the United States; such screening was a desirable model for the United Kingdom to follow.

Desired reforms

Health and Social Care Bill

NHS reforms proposed to split HIV funding through two different streams—with prevention and testing devolved locally, and treatment and care commissioned at a national level. This would disaggregate services, and was a risky move; the success of services in Brighton was related to the holistic approach that had been developed.

Funding was sometimes an ad hoc process at present—sperm washing, for example, was viewed as a fertility treatment rather than a prevention mechanism, with concomitant funding difficulties. It was important to ensure such services were still funded in any new regime; it was not enough to fund only mainline HIV services.

Service networks

The Royal Sussex covered a wide geographic area as a tertiary service. Best practice would feature a referral pathway which ensured that the Royal Sussex provided services for the most complex patients, whilst supporting other local hospitals to manage their services. ‘Financial teeth’ were required to establish this network as a commissioning model; there was presently no financial incentive to embrace it.

Treatment

Standards outlined in guidelines by professional associations needed to be enforced: problems relating to HIV should be seen to in specialist units, with other care dealt with elsewhere. This was often not the case.

Commissioning

Collaborative work between specialists and non-specialists—particularly GPs—needed proper financial reward. This would not only improve patient care, but would engender trust between patients and those outside of the specialist setting.

Post-exposure prophylaxis (PEP) was becoming increasingly common, with 25–30 prescriptions per month; the lack of a formal commissioning structure for its prescription needed to be addressed. Though payment by results was being established for HIV, it was not clear who was responsible for commissioning PEP, and there was a risk that it could fall through the gaps.

Department tour

Outpatient services

Overview

Genitourinary medicine (GUM) and HIV services were co-located. There were 27,000 patients per year in GUM services, of whom 1,700 were HIV and AIDS

service users. A hospital redevelopment, due to begin in 2012, would similarly co-locate outpatient and inpatient services.

Staff were multidisciplinary across both GUM and HIV services; this enabled flexibility according to service need, and a smoother patient journey to HIV services after a positive test result.

GUM services

The GUM clinic operated a mixture of appointment and walk-in services, including an under-20s walk-in clinic and appointment-only evening clinics. The clinic also operated a range of specialised services, such as a recognition system for commercial sex workers, advice services for HIV-positive and negative men who have sex with men and a clinic where chronic complaints could be seen by a consultant.

HIV services

The HIV unit offered a range of services, including annual general and sexual health screenings. An emergency HIV clinic, for urgent HIV-related concerns, was offered each day. This service could integrate, and facilitate appointments with, GP services where appropriate.

Upon being diagnosed, patients were seen in a new patient clinic, with routine follow-ups every 3 to 4 months. Staff from a range of specialisms, including research, pharmacy and nursing conferred to devise tailored treatment programmes; a level of integration not seen in a number of similar facilities. This enabled an integrated approach to care whilst also supporting the research functions of the hospital.

Inpatient services

Inpatient HIV care was provided in a six-bed unit within the main hospital building. Existing facilities were limited; the lack of negative-pressure facilities, for example, meant that TB co-infected patients had to be accommodated elsewhere. This would be addressed under the proposed redevelopment

The ward was covered by three regular members of staff, with consultant-led ward rounds two to three times each week. One of these rounds was attended by the full clinical team, including community specialists, representatives of the Sussex Beacon, the mental health team, a dietician and pharmacists; the aim was, to offer an integrated service.

Patient representatives

Patients were complimentary about the level of care received from staff on the HIV inpatient unit. However, they reported issues around service access in accident and emergency and primary care. One patient who had been admitted to the unit a number of times over the previous six months complained of having “hit a brick wall” in accident and emergency, with staff taking insufficient account of specialist input from the Lawson outpatient unit.

Elton John Centre

Overview

The Committee received a tour of the Elton John Centre, which combined the hospital’s research department with day care and psychological care facilities. It was one of between eight and ten designated research departments in the country which were located within large HIV centres. There were 35 active projects, which

featured extensive collaboration both nationally and internationally, with research support drawn from the medical school.

The centre operated as a ‘mini-outpatient department’; a unique model where clinical services were integrated into the trial. To recruit trialists, research nurses attended multidisciplinary care meetings to identify suitable candidates for clinical trials, before obtaining their informed consent for participation.

Funding

The Centre was not NHS-funded. Though decreasing numbers of trials were backed by pharmaceutical companies—trials were increasingly funded by grants from the Medical Research Council, the Department of Health or the National Institute for Health Research—they were still involved in research at the centre. This was not necessarily a negative point; Gilead and Bristol Myers-Squibb had supported testing initiatives without seeking to take ownership of data.

National Institute for Health Research

The establishment of the National Institute for Health Research (NIHR) in 2008 had benefited research in a number of ways. It had established comprehensive research networks, which meant that larger centres could be funded to support smaller research units—this had improved equality of access to clinical trials. Its establishment had also been crucial in engaging clinicians in clinical trials. Furthermore, its establishment had enabled funding for more ‘clinically relevant’ trials: for example, the centre was bidding for a £1.5m grant to study HIV and ageing in a national project.

Research implementation

Impetus from the Department of Health (DH) in translating and implementing research was important. Following research which demonstrated its efficacy, primary care testing was now a CQUIN⁵⁴⁴ target in Brighton; implementing this nationally required DH support. On a similar note, it was hoped that the *Time to Test* recommendations would be properly implemented.

Patient and staff views

Staff representatives

The Committee met with a number of staff representatives over lunch.

Pharmacy services

The role of HIV pharmacy services was highlighted. Brighton was the first location to establish a pharmacist-led antiretroviral clinic in 1996; and the hospital’s six HIV-specialist pharmacists played an important role managing adherence and drug interactions. Home delivery of medicines had been pioneered in Brighton and about 40% of those on antiretrovirals were now receiving their medicines in this way.

Costs

Due to the scale of provision in Brighton—the drug budget ran to £10m—the pharmacy had been able to negotiate antiretroviral contract prices similar to those of the London HIV Consortium.

⁵⁴⁴ Commissioning for Quality and Innovation payment framework: see http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_091443

Reform

Some staff voiced concerns about reforms to the NHS proposed in the Health and Social Care Bill. There had been a level of integration of HIV services in Brighton over the past 20 years which had positive results for patient care, adherence and research. Fragmentation of HIV commissioning under the proposed reforms—with prevention and testing, and treatment and care, being commissioned through different routes—posed a possible threat to this now-mature configuration.

Patient representatives

The Committee spoke to service users, who were positive about their experiences of HIV services at the hospital. The *CONNECT* service had been a sound development, reducing the number of appointments required when there were no complications.

Experiences in other services, notably primary care, were more variable. One patient was refused permission to register at a dentist; the same patient, based just outside of Brighton, had to actively alert their GP to their HIV status during consultations. It was speculated that these experiences were less frequently encountered within Brighton, where development of locally enhanced GP services had improved the levels of HIV training and expertise amongst GPs (see paras 90–91).

Duncan Selbie, Chief Executive, Brighton and Sussex University Hospitals Trust

Concluding the visit, Mr Selbie gave an outline of the future challenges and opportunities for HIV services—which were the “jewel in the crown” of the Trust. A proposed redevelopment of the hospital, for which £420m was set aside by the Secretary of State, would feature a bespoke clinical infections unit, and would allow the team to raise standards of care.

However, there were persisting challenges: for one, there needed to be better working with GPs; and inside the hospital, levels of routine HIV testing during hospital admissions needed to increase to meet CQUIN testing targets.

The next development aim was to better-integrate HIV care, and to work better with surrounding hospitals. The development of clinical networks would allow clinicians to tackle infections earlier and more effectively.

Sussex Beacon

The Committee visited Sussex Beacon, a HIV-specialist residential centre. There, the Committee heard presentations by staff at the Sussex Beacon, and then by Anna Bamford from the Community HIV Specialist Team within the Sussex Community NHS Trust. The Committee was then taken on a tour of the building by Andrew Powell, clinical manager at the Beacon, and spoke with Kat Williams, its Chief Executive.

Sussex Beacon presentation

Establishment

The Beacon opened in 1992, following the fundraising efforts of the local community. It was one of only two HIV-specialist residential centres in the UK; it provided residential and health management services, along with a service for women and families.

Administration

The Community HIV Team, the Sussex Beacon and the Royal Sussex General Hospital worked as a group of three, and integration had increased over time: a recent example was the introduction of medical workers onto the Sussex Beacon Board. The idea of a Sussex-wide HIV service network could alter funding arrangements; it was important to develop pathways that were sufficiently resilient to withstand any change.

Funding

Current turnover was £1.9m. 50% of this came from Primary Care Trust and statutory sources; the other 50% from fundraising and lottery funding.

The proportion of non-statutory funding had increased over recent years, a trend which was especially important in the fiscal climate. The Women and Families Service had received a £478,000 grant from Big Lottery over 5 years, and the Monument Grant had awarded funding for health management services.

Overall, the funding environment was unclear. The PCT grant to the Beacon, as an example, was frozen for two years despite increasing costs. Fundraising would be vital to the maintenance of services, but it was also important to rationalise provision where possible.

Services

Residential care

Step-down care was provided for those recovering from serious illness. Staff were involved in adherence and side-effect management, as well as end-of-life care in a small number of cases. These services were a cheaper alternative to acute inpatient stays where appropriate.

Health management services

Health management services sought to “fill key gaps”, such as through anxiety management and sleep support.

Women and families service

The Beacon provided a monthly women and families service, with capacity for casework, to a cohort of more than 50: a significant proportion of women affected

by HIV in Brighton. There was also a Women's Forum Group, which liaised with community and local HIV services. These services provided peer support and counselling, and addressed stigma.

Reform

The potential effects of structural reform to the NHS upon HIV services were uncertain. However, there were aspects of current arrangements that suggested support would continue: HIV was recognised as a local priority, and a link nurse had established connections with primary and community care providers. This was bolstered by the knowledge that the Beacon provided additional value through its responsiveness and ability to draw on additional fundraising streams.

Community HIV team presentation

Introduction

The Community HIV Specialist Team was part of the Sussex Community NHS Trust. In operation since 2002, the team brought together healthcare, social care and mental health into one service. The team included HIV nurses, mental health workers, psychiatrists, social workers and health promotion practitioners.

Services

The core business of the service had a number of facets. One element was continuity of care for those newly diagnosed or recently discharged from hospital. Another was around social care interventions, with personalised budgets for service users. Health promotion was an emerging area of prominence where the team was keen to do more work. All together, the facets of the service—boosting adherence levels, promoting disclosure and managing risk behaviours—comprised one part of HIV prevention within Brighton.

Care model

Everything began with an initial assessment and the development of a care plan in agreement with the patient. This outlined intervention levels and the care pathway. Subsequently, partnership working was fundamental. A community multidisciplinary meeting allowed clear remits to be set among community providers, partners at the Royal Sussex General Hospital and in generic services; and the patient was proactively engaged through case conferences throughout the process. As HIV shifted from an acute to a chronic illness, this approach allowed greater self-management and was potentially empowering for patients.

This partnership working was a desirable outcome: it ensured that care could be properly co-ordinated, allowing expertise to be concentrated on appropriate cases. To this end, the HIV social worker for the team was now located within Brighton City Council, to ensure one port of call for social care services. The team was not aware of a similarly integrated model anywhere else in the country.

Development

The team was constantly learning from both service users and providers to develop the model of working. Learning was distributed at national conferences, with the aim of spreading best practice elsewhere: personalised care plans, now commonplace, were in place for HIV well before other areas.

There were, though, ongoing challenges. The isolation and stigma felt by patients remained a concern, and there were issues around patient disengagement from care.

Patient views

The Committee met a service user at the Beacon, who spoke positively of the quality of service provision, particularly the multidisciplinary care. Patients were given control of their own drug schedules; this was a positive and empowering part of care.

St Peters Medical Centre

The Committee visited St Peters Medical Centre, a six-GP practice responsible for 11,500 patients, of whom approximately 120 were HIV positive. Presentations were given by Dr Jonathan Wastie, a GP at the practice, Gavin Stedman-Bryce, a consultant, and PCT representatives.

Funding

The most effective way of encouraging GPs to engage more directly with HIV would be to ensure that funding was allocated to successful delivery of HIV-related services. This could be through the Quality and Outcomes Framework or through a Local Enhanced Service, such as the one operating in Brighton.

Local Enhanced Services

Overview

The practice was one of 26 in Brighton that held a Local Enhanced Service (LES) contract for HIV care, managed through the Primary Care Trust. The LES required staff at participating practices to attend a two-day training course provided by the Lawson Unit and local HIV specialists.

Subsequently, participating practices had to undertake an annual health-check on each of their HIV positive patients, a practice similar to that for patients with diabetes and other chronic conditions. The aim of the health check was to monitor health and identify issues which required a response or treatment within the primary care setting. This relieved pressure on secondary and GUM services by providing a broader primary care response to HIV-positive patients; this was welcomed by secondary care representatives from the Lawson Unit. Prescription responsibility remained with specialists.

Normalisation

The main benefit of the LES provision was that it “normalised” the issue of HIV for primary care practitioners. The provision of such services encouraged primary care to engage more directly with HIV and to provide a level of care that would be thought routine for other ‘chronic’ patients such as those with diabetes. The offer of a HIV test to new registrants was also a potentially important step towards such “normalisation”, by engaging patients and incorporating HIV more fully into routine medical discussions.

Collaboration

The LES had proven important in building links between primary care practitioners and HIV specialists based within the hospital. These links began with the initial training course and were developed through ongoing patient management. Such links were beneficial in building knowledge and confidence on HIV amongst primary care; they were also important in developing an integrated patient pathway.

Time to Test pilots

The practice had taken part in a pilot testing programme (one of eight nationally) in which HIV tests were offered to all new registrants as part of an initial health check. This pilot project had run for six months from May 2010 across ten practices in Brighton.

During this time approximately there were 5,000 new registrations at the participating practices. 2,400 of those new registrants completed health checks, and all were offered a HIV test. Approximately 1,450 people (60%) had accepted the offer of a test, two of whom tested HIV-positive.

The 950 patients who declined the offer of a test were offered the opportunity to complete an explanatory questionnaire, and around half did so. Despite having refused a test, over 80% of those surveyed thought that GP testing was a good idea and 91% thought that general practice was an appropriate setting for such testing to take place.

Results from this and the other national pilots had been fed back to the Department of Health for evaluation. This evaluation would include assessments of acceptability, feasibility and cost-effectiveness. In the interim period, six of the ten participating practices in Brighton were continuing to offer HIV testing as part of their new patient health check, without payment for doing so.

APPENDIX 5: VISIT TO LONDON CLINICS 31 MARCH 2011

The Committee visited the Chelsea and Westminster and Homerton University hospitals in London. Lord Fowler, Baroness Gould of Potternewton, Baroness Healy of Primrose Hill, Baroness McIntosh of Hudnall, Baroness Masham of Ilton, Baroness Ritchie of Brompton and Baroness Tonge were in attendance.

Chelsea and Westminster Hospital

Acknowledgments

The Committee heard a number of presentations from staff members at the Chelsea and Westminster hospital, and received a tour of both inpatients' and outpatients' services. The visit concluded with a short question and answer session.

The Committee would like to thank the following personnel from the Chelsea and Westminster Hospital Foundation Trust for their work in arranging activities on the day, and for their time in providing information to the Committee:

- Professor Sir Christopher Edwards, Chairman, Chelsea and Westminster Hospital NHS Foundation Trust
- Heather Lawrence OBE, Chief Executive, Chelsea and Westminster Foundation Trust
- Dr Simon Barton, Clinical Director
- Nicola Sprigens, General Manager for HIV, GUM, Dermatology and Gynaecology
- Dr Anton Pozniac, HIV Service Director
- Dr Mark Nelson, Service Director, HIV Directorate
- Dr David Asboe, Lead Clinician, Kobler Clinic
- Professor Brian Gazzard, Director of HIV/GUM Clinical Research and Education
- Jane Bruton, Clinical Nurse Lead for HIV
- Lesley Sinclair, Charge Nurse, Thomas Macaulay Ward
- Simon Farnworth, Clinic Manager, Kobler Outpatients
- Dr David Hawkins, Lead for HIV Family Clinic and Obstetric Liaison Service
- Dr Ann Sullivan, Consultant in Genitourinary Medicine
- Dr Alan McOwan, Service Director for Sexual Health
- Paul Decle, Patient Representative and Chair of the Frontline Patients Forum
- Renae McBride, Communications Manager

Multidisciplinary team presentation

Overview

Professor Sir Christopher Edwards, with colleagues, provided an overview of the services delivered at the hospital. The Chelsea and Westminster provided services for approximately 5,000 people living with HIV, making it the largest centre of its kind in Europe. The volume of patients was originally a result of the hospital's

location but over time had also become a reflection of the high levels of clinical expertise at the hospital.

The hospital was a Foundation Trust; it was the view of the staff that this had been important in allowing the hospital to reduce bureaucracy and determine how it could best deliver services effectively. This greater flexibility allowed the hospital to be more responsive to patient feedback, for example through the delivery of test results by text message. The status gave executives the confidence to take risks, inspired by the innovation of clinicians. An example of such impetus was the Dean Street sexual health clinic.

Patient cohort

A large proportion of patients were men who have sex with men. However, staff explained that the HIV cohort was becoming increasingly diverse over time.

Costs

Sexual health services accounted for approximately 25% of the clinical contract income to the Trust; HIV services alone accounted for £54m (between 15% and 20%) of the Trust's total expenditure of £284m. However, clinicians highlighted that the annual costs of HIV care—approximately £7,000 per patient—compared favourably to the treatment costs for other chronic conditions, such as the £50,000 annual cost per patient for renal dialysis.

The resources required for HIV care had, in the past, brought about difficulties with commissioners. The 'walk-in' nature of sexual health services and the ongoing costs of managing HIV had deterred commissioners from supporting efforts to expand prevention work and testing services to engage hard-to-reach groups. However, clinicians had worked with commissioners over time to gain support for this outreach work, and in the process developed commissioning approaches which acknowledged the public health benefits of outreach and the need for a specialised approach to HIV.

Treatment

The management of HIV drugs remained a specialist area. Interactions and side-effects required detailed technical knowledge, which could only be built up through sustained experience of treating a diverse patient base.

Although a specialist centre, patients often presented with a varied and complex range of conditions traditionally dealt with in primary care. In addition, ongoing screening and health checks of HIV patients ensured that other health issues were quickly identified, contributing to a high standard of overall medical care.

Staff operated a 'virtual clinic', where a full team was available to consult with clinicians from across the country, both over the phone and online. This enabled staff to use their expertise to support effective treatment nationwide.

Testing

Having gained the support of commissioners for the development of outreach work, it had become increasingly important in the diagnosis of patients. Successful initiatives included the establishment of the Dean Street Clinic in Soho; and the development of mobile walk-in facilities, which were recently used to establish a men's health clinic at Stamford Bridge, the home of Chelsea Football Club.

56 Dean Street presentation

Overview

Dr Alan McOwan gave a presentation on services delivered at 56 Dean Street, which was an NHS sexual health clinic in Soho offering testing and treatment services. With more than 50 clubs and bars for MSM within a 500 metre radius—where monitoring indicated that 12% of patrons were HIV-positive, of whom 42% were undiagnosed⁵⁴⁵—there was a high level of unmet need in the area. The clinic was ideally positioned to deliver services and outreach to a group at the highest-risk of contracting HIV.

The overriding message was: if world-class services were provided in the right place, at the right time, with patient input, then services would be accessed. This approach was appropriate for wider implementation, if supported by cost-effectiveness data.

Cohort

Although the service was in a location where MSM venues were concentrated, it was used by a broad range of people. The clinic was close to a significant and often hard-to-reach Chinese community; the team's work within that community had been rewarded with a Department of Health Partnership Working Award. There were also a significant proportion of women, who often utilised the unit's family planning services. The team also worked with the Terrence Higgins Trust to provide services for sex workers.

Testing

The aim of the clinic was to reduce the fraction of those living with HIV who were undiagnosed, by increasing levels of testing. Opening times were flexible; rapid tests were used, which delivered results within 20 minutes; and staff visited bars and saunas to offer testing services. It was a successful strategy: 1 in 17 of all HIV diagnoses in the United Kingdom were made at the clinic. This was all part of normalising testing. The aim was to ensure that those engaging in risk behaviours checked their HIV status annually.

Treatment

As an open-access clinic in a prominent location, capacity was a concern. However, its setting allowed the team to target its resources, and ensure rapid referral into care for those diagnosed.

As the patient cohort grew, maintaining the standard of care was imperative. There were a number of methods used to streamline provision. Stable patients were seen only once a year, and emailed results to abrogate the need for an appointment. There was also a telephone clinic, which offered virtual consultations and triage in order to free up clinic time. This had ensured that there were more appointments available to patients, despite a 16% rise in caseload.

Monitoring was crucial; even stable patients experienced crises. This was the purpose of the multidisciplinary team. Though the process was seamless for the patient, this resulted from a behind-the-scenes framework which brought together a variety of specialisms to ensure that staff were able to respond to a diverse range of issues.

⁵⁴⁵ Dodds J.P., *Sex Trans Infect*; 83; 392–396

The success of the clinic was linked to its recognition that it was providing a service to users, as well as being a healthcare facility. The service was quick, comfortable, and outward-focused, and responsive to the needs of its users—it was one of only two NHS sexual health clinics in London open on Saturdays, for example.

HIV family clinic and obstetric liaison service presentation

Dr David Hawkins then gave a presentation on the HIV family clinic. The clinic was designed to attend to the needs of HIV-positive women and their children (even if the children were exposed but uninfected). This included services both during and after pregnancy, sexual health and conception advice for women and their partners, and psychological support for both mothers and children.

Mother-to-child transmission

The rate of HIV transmission from mother to child was less than 1%, with only 2 cases observed in over 7 years and more than 250 deliveries. This compared to a national rate of mother-to-child transmission of between 3% and 4%.⁵⁴⁶

Success was partly down to high rates of antenatal testing. More than 99% of pregnant women were tested for HIV at Chelsea and Westminster, compared to a national average of around 95%.⁵⁴⁷ It was also linked to the earlier commencement of antiretroviral therapy during pregnancy, adopted in accordance with accumulating scientific evidence.

Cohort

There were more than 1,000 HIV-positive women within the family clinic and obstetric liaison service, most of whom were of childbearing age. 80% of the cohort was of sub-Saharan African descent, although service users were increasingly acquiring HIV within the United Kingdom.

Each year there was an average of 40–50 pregnancies, with around 20 women pregnant at any one time. There were around 15 infected children in the cohort, several of whom were in transition to adult care services.

Services

The clinic provided practical reproductive, family planning and sexual health advice, as well as clinical services such as sperm washing, and pre- and post-exposure prophylaxis where appropriate.

The team was multidisciplinary, including HIV and GUM specialist doctors, health advisers, midwives, obstetricians and paediatricians. The service also had specialist paediatric nurses and a clinical psychologist. This ensured the capacity for early and comprehensive care, preventing future ill-health.

In light of the social circumstances of the cohort, the service had strong links with community services; and at times, social workers and legal advocates. Such a model of shared care ensured that patients were cared for appropriately according to their needs.

⁵⁴⁶ Health Protection Agency, Data Tables of the Unlinked Anonymous Dried Blood Survey of Newborn Infants: Surveillance update 2010: http://www.hpa.org.uk/web/HPAwebFile/HPAweb_C/1287144874352

⁵⁴⁷ NHS Screening Programmes, Infectious Diseases in Pregnancy Screening Programme, 2008–2009 Annual Report (latest available).

Research

There was an active research unit within the service, which was evaluating the metabolism of newer antiretroviral drugs in pregnancy. The service had also co-founded—and co-hosted—the London HIV Perinatal research group.

Inpatients' services

Overview

Professor Brian Gazzard and Dr Mark Nelson led a tour of inpatient facilities. Inpatient services were provided on the Thomas Macaulay Ward. This was a 20-bed unit, which included four negative pressure rooms for use in treating patients co-infected with tuberculosis. The ward was amongst the largest of its kind in Europe and was recognised as a centre of excellence. A number of patients whom the Committee met had been referred to Chelsea and Westminster from across the country owing to its ability to treat particular medical complexities and conditions.

The ward dealt with a very diverse range of complex conditions in people living with HIV; conditions discussed with patients on the day included heart attacks, lymphatic conditions, pneumonia and mental health problems. Extensive support services were available to patients, including chaplaincy, dietary advice and occupational therapy.

Patient pathway

Multidisciplinary working figured strongly, with a daily ward round and a weekly meeting with representatives from several disciplines to plan and assess the care needs of all patients.

Each patient had primary and associate nurses assigned to them during their stay; these same personnel were reassigned to patients on any return visits. Patients spoke positively and warmly about their relationships with staff, highlighting that this continuity of care was important in building a relationship of trust. Continuity was also important in the management of a long-term chronic condition; some patients reported negative experiences with agency or contract staff who had demonstrated a lack of understanding of their particular condition and needs.

Patient choice and independence was seen as important to the overall ethos of the ward. This was reflected in choice around all aspects of the daily hospital routine, an open visiting policy and strong representation from patient groups in management board meetings.

Kobler Day Clinic

The Kobler Day Care centre, located next door to the inpatient ward, offered specialist day care services for people living with HIV. This was designed as a service to maintain the independence of patients who needed medical attention who may otherwise have required admission into hospital. In this respect, it was a transitional facility between outpatient and inpatient care. Services included HIV oncology clinics, follow-ups for individuals after discharge and the facilitation of patients through to the inpatient ward itself.

This was a new initiative, established in January 2011, and was already dealing with more than 100 patients a month. In discussion, patients suggested that this day care provision was a positive development and helped to increase access to care.

Part of the purpose of the clinic was to operate as a 'telephone triage' service, directing patients to the appropriate place for their problem. The aims were

manifold: to reduce HIV patient admissions to accident and emergency wards; to support patients who had problems accessing GP services; and to provide links to wider oncology and sexual health services. Despite the triage model, there remained significant numbers of 'walk-in' arrivals.

Research

The ward was strongly integrated into the wider research efforts of the HIV unit at the hospital, and staff on the ward regularly contributed to research projects and publications.

Kobler outpatients' clinic

Dr Simon Barton led a tour of the Kobler outpatients' clinic. As an outpatient unit, it dealt with the majority of patients whose condition was not likely to necessitate admission into hospital.

Overview

The clinic was a specialist centre, with expertise in a range of fields, including co-infections and research into the ageing HIV population.

Of the 6,000 patients living with HIV registered at the Trust, 5,000 were on treatment, and 3,800 attended the Kobler clinic. Patients came to the unit by referral: either following a new diagnosis in primary or acute care, or through self-referral. There were 80 to 90 new patients per month; patients often transferred in due to the centre's renown as a centre of excellence.

Pathway

The pathway began with a baseline health assessment by a health adviser, and then with a first visit to the Kobler clinic a fortnight later. The process orientated service users into the clinic.

Patient support was an important element of care. Particular facets of early support revolved around partner notification, and advice on prevention and on telling children and family members of the diagnosis.

Funding

The calculation of funding streams was complex, and featured two elements. First, the London HIV Consortium was informed of the hospital's caseload; at the same time, Health Protection Agency data tracked the numbers of people from each area accessing services. From synthesis of these data, the London Specialised Commissioning Group (where the Consortium was based) calculated the cost to fall upon each Primary Care Trust. The system ensured that disproportionate burdens were not placed on Trusts where large patient cohorts from across London were treated, such as at Chelsea and Westminster.

Nursing

The role of the nurse had changed over the previous 10 years, most noticeably after the development of highly active antiretroviral drugs (HAART). Treatment advances meant the patient cohort was expanding, but staffing levels were static.

Capacity pressures had led to innovations such as enhancing the role of healthcare assistants. They were responsible for chaperoning, patient support and orientation, amongst other tasks, and they helped to free up the time of specialised nurses.

Care in the clinic was organised in 3 consultant-led teams, with junior and senior nurses involved in care delivery. Associate nurses gave skilled support to the team

through treatment support, health promotion and psychosocial support. There were also several specialist services in which nurses played a role: care for young patients; women's services; and mental health and psychological support. Additionally, a nurse specialist was co-leader in the hospital's over-50s clinic.

There was an emerging incidence of Hepatitis C in the HIV-positive cohort of men who have sex with men. A specialist role was emerging for nurses in caring for co-infected patients and also in the prevention of onward transmission. 57 co-infected patients were seen during 2010, with a cohort of 30–40 at any one time. The work involved health promotion, risk reduction counselling and monitoring.

Pharmacy

The clinic had a dedicated pharmacy on-site, which took pressure away from other staff. The role of the pharmacist was an advancing specialism and had myriad benefits for the hospital: home delivery of drugs had been developed, which saved money for the hospital and was more convenient for patients; and medicines were better-managed to avoid stockpiling—medicine management had saved the hospital £250,000.

Helping patients to adhere to treatment as drug regimes became a lifelong commitment was an increasingly important part of the role of pharmacists. Maintaining people on antiretrovirals was critical to treatment success, and a way of pre-empting crises. The work done on adherence in relation to HIV therapy was translating to other areas of medicine.

Research

Research was embedded with clinical care. This model was increasingly common, but had been pioneered by Brian Gazzard at the Trust.

Clinical trials

The research unit conducted clinical trials of all phases. As well as bringing new things to patients, such trials were an important part of staff learning. Focus at present was around drug interactions. Managing side-effects as well as blood concentrations was a major challenge, and required collaboration with GPs; it was thus an area of significant research interest.

Research was funded through the St Stephen's AIDS Trust. Funding came from industry and academic bodies, with more than 50 studies at any one time. Trials often received co-funding from other sources, and pharmaceutical companies provided trial drugs for free. Research, therefore, was often a cost-effective exercise. Additionally, the multiple funding streams and separate legal identity of the Trust ensured that research was patient-centred, irrespective of internal or external pressures.

GP training courses

Researchers had developed a Sexually Transmitted Infection Foundation (STIF) course for GPs, which sought to ensure universal standards for sexual health in primary care.⁵⁴⁸ It had been rolled out across the country, with approximately one course per week taking place somewhere in the United Kingdom; over 10 years, more than 12,000 GPs had taken part. There was a similar two-day course for HIV. The key message on both courses was the need for greater testing in a primary care setting.

⁵⁴⁸ See: http://www.bashh.org/education_training_and_careers/stif

Ageing clinic

As survival rates increased, the HIV cohort was ageing; approximately 30% of HIV-infected individuals in the United Kingdom were 50 or older. To compound this, research data showed that HIV infection and antiretroviral agents caused premature ageing, as the inflammation they cause affected the regeneration of cells. Furthermore, non-AIDS-related co-morbidities were more frequent in HIV-infected individuals at an earlier age than for those who were HIV-negative—HIV-positive people in their 40s had multiple co-morbidities as often as HIV-negative people in their 60s.

These series of factors made management of HIV infection in older patients particularly complex. A service at the Kobler Clinic was therefore dedicated to HIV-infected patients over 50. Its focus was on the management of renal and cardiovascular disease, osteoporosis, mental health, and neurocognitive disease. The clinic also facilitated direct access to research, particularly studies dedicated to the investigation of co-morbidities.

Commissioning

At present, drugs were commissioned on a pan-London basis. Though commissioning at a national level had been recommended by clinicians, the Department of Health stated in 2010 that it did not envisage a shift in commissioning arrangements was forthcoming.

Primary care

The involvement of primary care was crucial. In the area around Chelsea and Westminster, GPs were anecdotally found to be responsive to greater involvement. Staff had found that the more active that hospital staff were in involving GPs in patient management, the more actively they had responded. However, such engagement, which included one-to-one phone consultations, was time-intensive. It would be important to ensure resources were allocated to these efforts to ensure they were successful.

Question and answer session

Testing

Expansion of testing

The key to the expansion of testing was the engagement of patients; both through raising awareness of the ease of testing, and normalising testing more broadly. The team at Chelsea and Westminster were active in research to facilitate development on both fronts.

HINTS

A Department of Health-funded pilot, *HIV Testing in Non-traditional Settings* (HINTS), sought to test the acceptability and feasibility of expanding testing across accident and emergency, primary care, acute admissions and dermatology outpatients.

6,200 tests were offered, with 4,100 (67%) patients accepting. There were eight new diagnoses, and two further diagnoses through partner notification; all were successfully transitioned into care. 92% of patients found it acceptable to be offered the test, which included 85% of patients who declined a HIV test at the time.

The diagnosis rate of 1.9 diagnoses per 1000 tests was classified as cost-effective according to data from the United States, but it was important to build a UK evidence base on this front as well.

Though the study demonstrated the acceptability and feasibility of the approach, there were significant staff education and training needs identified for such processes to be sustainable.

HEDS-UP

A subsequent study, *HEDs-UP NW London*, funded by Gilead, sought to roll out the accident and emergency element of the *HINTS* programme and examine its sustainability through different models of delivery.

The taking of saliva samples were shown to be more acceptable and quicker, overcoming barriers to testing. There was a difference in cost, however, owing to more expensive equipment for saliva testing. Despite this, the spread of saliva testing was to be encouraged.

Both studies sought to develop the evidence base for the normalising of testing in other departments. The ultimate aim was to encourage the setting of testing targets with linked financial incentives.

Indicator disease research

Research was being conducted into the HIV prevalence in patients with eight HIV indicator conditions as part of a pan-European survey. The survey covered colposcopy, dermatology, haematology and oncology (in particular those with lymphomas). There had been 860 tests to date, with 4 new HIV diagnoses. The study sought to provide cost-effectiveness data to support HIV testing for patients with indicator conditions.

Testing in prisons

To expand testing in prisons, prisoners required enough free time to be tested. It was therefore important for any screening programmes to be nationally-led, as local commissioners often lacked interest. Public Health England offered an opportunity in this respect.

Prevention

Prevention needed a national push to put it on the agenda; it was not appropriate to delegate the task to individual PCTs.

The biggest preventive measure would be the reduction of the undiagnosed fraction of those with HIV; in the United States, 50% of new infections came from the 25% of people living with HIV who were undiagnosed. Getting those with HIV onto treatment worked preventively: adherence to treatment vastly reduced levels of transmission. The success of antenatal HIV testing on both fronts was remarkable.

Innovative outreach to access those who were not testing was crucial, as was expanding testing into different settings—if GPs normalised testing, patients were more likely to test. The role of hospital staff in working with patients to reduce risk behaviours was also important.

Homerton University Hospital

The Committee visited Homerton University Hospital. The Committee was given a tour of the sexual health unit, followed by a question and answer session with patient representatives and staff.

The Committee would like to thank the following personnel from the Homerton University Hospital Foundation Trust for their work in arranging activities on the day, and for their time in providing information to the Committee:

- Nancy Hallett OBE, Chief Executive
- Dr John Coakley, Medical Director
- Professor Jane Anderson, HIV Consultant
- Dr Iain Reeves, Lead clinician for HIV
- Godwyns Onwuchekwa, Patient representative
- Jacqui Hale, Lead nurse
- Danna Millett, Nurse for testing and patients
- Zarqa Mohammed, Specialist pharmacist
- Sarah Zetler, Clinical psychologist
- Dr Sarah Creighton, Consultant in HIV and community sexual health services
- Matt Wills, Social care coordinator
- Lynne Sivour, Midwife
- Maryam Parisaei, Consultant midwife
- Daniel Waldron, General Manager
- Margaret Fadojutimi, Operational manager
- Tonya Chalker, Communications manager

In addition, the Committee wishes to thank patient representatives who attended on the day and who relayed their experiences of living with HIV.

Hospital tour

Services

There was a single entrance to the sexual health clinic as a whole, and HIV services were part of a broader suite of genitourinary medicine services. Though this integration was an issue in terms of capacity as patient numbers rose (there were only two HIV consulting rooms), it facilitated a holistic approach to HIV-positive patients, and reduced stigma around HIV.

Genitourinary medicine services were open-access, but all HIV services were by referral. 25% of referrals came in Homerton came from primary care, the highest rate in London. The strong relationship with primary care was also clear from the proportion of patients at the unit disclosing their HIV-positive status to GPs; again, this rate was the highest in London.

Female patients

A significant portion of the patient cohort was female, but the unit had only a limited ability to provide for childcare. As a result, the hospital had developed the *Alongside You* programme, where HIV-positive older women volunteered to care for the children of patients at a local church during appointments.

Living with HIV in poor circumstances was profoundly difficult for women, and patients faced a number of difficult situations after diagnosis; partner notification and HIV testing for their children were immediate issues, but housing and benefit problems were also common.

Notification

The difficulties for patients in disclosing their HIV status was noted. It was a particular challenge for patients to inform their children, but partner notification was also complex.

Confidentiality

Confidentiality was imperative, and records at the clinic were kept on a separate system from the rest of the hospital. However, it was a challenge to maintain confidentiality given the restricted capacity in which the service operated.

Question and answer session with staff members

Patient cohort

There were 813 HIV service users, of whom 56% were women. 67% of the cohort was black African, 17% were black Caribbean, and 11% were white British.

The hospital took on around 120 new patients, and lost between 30 and 50, each year—a net increase of at least 70 users. The flux was partly down to the fact that Hackney was a very mobile community, with a significant proportion of residents in the immigration system. However, some patients were still dying of HIV and AIDS.

Overview and challenges

Staff from across HIV and GUM services were asked about their area of expertise, and the main challenges incumbent upon them.

Nursing

Nurses were integral in work to expand the reach of HIV testing, both into other departments of the hospital and more widely. There were a number of barriers to doing so: amongst others, staff attitudes to testing, capacity problems, and society's perceptions of HIV.

Consultants

The most important development required was the construction of a service model that met psychosocial and medical needs, with integrated community services. The hospital had a dedicated social and medical care co-ordinator who sought to enhance this integration; the challenge was to develop such a model in the absence of a commissioning framework to facilitate it.

As patient numbers increased, and patients lived for longer, capacity at the clinic was increasingly stretched; combined with a straitened financial climate, it was increasingly challenging to maintain the quality of treatment and care—albeit one that had to be addressed.

Commissioners and managers

The main challenge was to change the way that hospitals worked, and how they look at patients and their needs: needs had to be addressed, rather than responsibility being sidestepped. This shift was required in a difficult financial

climate; trying to “say yes more than no” to clinicians, therefore, was an additional test.

Mental health

Many patients had little exposure to mental health services. HIV patients were screened for mental health issues, and it was important to provide pathways for referral. However, there were few services available, despite the increase in patient numbers.

Midwives

There were 40 pregnancies per year at Homerton, but there had not been a HIV-positive child born since 2005. Midwives sought to coordinate different service strands to help their patients; the varying needs were testament to the importance of a multidisciplinary team. Funding cuts had somewhat eroded the role, and such cuts risked the quality of services provided.

Treatment

General

There was huge publicity around HIV and AIDS at the start of the epidemic. However, despite radical change in the nature of HIV as medicine advanced, public awareness had not kept pace. As a result, HIV was often seen as just a sexual health issue, with a concomitant lack of engagement outside of specialised services. This was changing over time.

The importance of holistic, integrated services was highlighted. Strong links had developed across different specialisms, with regular meetings and support structures proving important in providing a high level of patient care. There was a risk that this complexity of care across disciplines would not be sufficiently recognised within the new payment-by-results HIV outpatient tariff.

Social care coordination

The employment of a social care coordinator was an important element of service integration, linking services across other local agencies and supporting the wider care needs of people living with HIV. This was important in supporting adherence to antiretroviral therapies.

Staff highlighted the complexity of service design in London, with tightly constrained borough councils, coupled with differing boundaries of medical and other agencies, producing both commissioning and patient access problems. The social care coordinator played an important role in allowing patients to navigate this complexity.

Mental health

Many patients presenting at Homerton were of African origin, and a number of them suffered from post-traumatic stress disorder, compounded by a HIV diagnosis. Staff had worked hard to engage such patients with mental health services. In addition, as the cohort of people living with HIV aged, levels of mental health problems were increasing.

There was often too little responsibility taken when patients with HIV had mental health issues. The hospital was taking steps to address this with the employment of a clinical psychologist.

Mental health support was vital in promoting adherence to therapy and producing positive treatment outcomes. Commissioning structures demanded that mental

health services were funded from the HIV treatment budget, rather than general mental health services. The rigid structure often resulted in a silo mentality, which meant that mental health services were not engaged for HIV-positive patients who needed them. This failed to put patients first.

Costs

Antiretroviral drugs were expensive but cost-effective; nonetheless, funding pressures would only increase as patients lived longer. There were opportunities for Homerton to pioneer models of commissioning to contain cost increases which were more generally applicable elsewhere.

Commissioning

Procuring drugs on a regional basis, as with the London HIV Consortium, was a good idea, but there was an argument for national-scale procurement. Regardless of how commissioning was arranged, commissioners failed to give enough thought to the long-term impact of their decisions.

Prevention was often organised at a PCT level; it needed to be more joined-up. The London Sexual Health Programme had ‘too little muscle’ in this respect. More broadly, there was insufficient focus on prevention within commissioning. This was compounded by the lack of a vocal lobby for prevention when funding decisions were made.

Overall, there was insufficient oversight or coordination of commissioning in the area. In mental health for example, boundary issues made it the responsibility of the PCT in some areas, and the Foundation Trust in others.

Testing

Within the hospital

Increasing the uptake of HIV testing was important, both within the sexual health context and elsewhere. One major barrier to testing was the incorrect perception amongst healthcare professionals that “pre-test counselling” was required. Proper, engaged consent was required for all blood tests; but this was neither necessarily difficult nor unique to HIV, and studies had shown that it was very acceptable to patients. The key was to adopt an engaged approach to consent in all departments.

Primary care

The hospital had undertaken partnership work in recent years with GP surgeries in Hackney to support HIV testing in primary care settings. This work included support for *RIVA II*⁵⁴⁹, a PCT and Department of Health-funded pilot of finger-prick testing in GP surgeries. If pilots like *RIVA II* and *Time to Test*, another DH-supported initiative, were shown to be effective, implementation had to be supported.

Homerton also encouraged the greater involvement of GPs in patient management. Rates of patient disclosure to GPs were high, as were the levels of contact between the hospital and primary care. This was proving successful in encouraging GP familiarity with HIV. As experience levels and involvement in dealing with HIV increased, so did testing rates.

The proper organisation of services, including the manner of hospital staff involvement, would be important in enhancing the role of GPs in ongoing treatment and care going forward.

⁵⁴⁹ Rapid Infectious Virus Assay II.

Prevention

Staff highlighted the difficulties faced when contact tracing following a new diagnosis of HIV. Contact tracing was important; particularly for heterosexual HIV infections, where those possibly infected were far less likely to undergo routine testing. Existing systems could be improved, but an effective approach had not yet been developed in the United Kingdom.

Reform

Staff noted that proposed reforms in the Health and Social Care Bill were unclear. The HIV community needed to be more proactive in outlining the optimum configuration to the Government to stimulate change. The ideal service configuration involved linking together health and social care; a holistic service where all elements of medical and social care could be addressed in one place.

The fragmentation of commissioning responsibilities, as proposed in the Health and Social Care Bill, made such an approach more difficult. The addition of a networked level above local authorities and GP Commissioning Consortia [now NHS clinical commissioning groups], to coordinate their work, was one way to alleviate concerns. There were other concerns around the Bill; in particular, it was felt that local authorities did not have sufficient expertise to take on responsibility for public health campaigns around HIV. National-level commissioning of HIV treatment and care, however, was a positive development.

Some staff also expressed concern about the potential impact of voluntary sector funding cuts and the way in which these may impact HIV support and care groups.

Question and answer session with service users

Patient representatives gave their views to the Committee across a range of issues.

Stigma and discrimination

Society suffered from a refusal to accept lifestyle choices, which often meant that, for many people, HIV was linked to moral and religious judgments. Within communities, particularly diaspora, so closely integrated, such disapproval could disconnect people from support networks. Faith communities needed to be held to account where their teaching on HIV was discriminatory or stigmatising.

Outside of the HIV community, there was widespread ignorance, compounded by discriminatory media reporting. It had to be tackled to overcome discrimination. Education across churches, schools and the workplace was required. The voluntary sector was engaged with faith communities and employers. Such initiatives were important in broadening minds and dispelling myths; however, the Government also had a part to play in raising awareness.

Disclosure

It was important to engender a culture where revealing one's diagnosis was acceptable. Though peer support groups and specialist support from voluntary organisations could help patients to disclose their status to others, society's response to a diagnosis needed to change.

Without such a culture shift, disclosure was a major challenge for those with HIV. Issues around how partners would react, and the impact on the children of those diagnosed, were raised as particularly prominent concerns. One patient received a negative and violent reaction after notifying their partner.

Medical issues

Medical issues faced by service users included mental health problems, glaucoma and hypertension. As well as attending to these medical needs, the hospital supplied translation and other support services. The help provided by the psychology department was noted, as was the support of clinic staff more generally.

APPENDIX 6: VISIT TO LEEDS 9 MAY 2011

The Committee visited a needle supply programme, Leeds General Infirmary and two community service providers in Leeds. Lord Fowler, Baroness Gould of Potternewton, Baroness McIntosh of Hudnall, Baroness Masham of Ilton, Lord Rea, Baroness Tonge and Professor Anne Johnson (Specialist Adviser) were in attendance.

The Committee would like to thank all of those personnel named throughout this note for their work in arranging activities on the day, and for their time in providing information to the Committee.

A. Needle supply programme

The Committee visited a needle supply programme located in the city centre. The facility was provided as a specialised service in the basement of a *Boots* pharmacy, supplying clean injecting equipment and methadone. Supply of methadone required a prescription and participation in a drugs treatment programme; supply of injecting materials did not. There was no requirement for service users to be registered with a local GP practice or health service.

Before receiving injecting equipment, users were required to complete a form outlining their requirements and specifying what the materials would be used for. The form had been designed with input from service users. The overall number of injecting drug users in the city had declined in recent years. The large majority of those accessing the city centre facility were heroin users; other needle supply facilities in the city had, however, seen increased numbers of steroid users accessing services in recent years.

Service users were encouraged to return used needles in exchange for new ones, but this was not mandatory. This approach was part of the harm reduction ethos of the service; the pharmacy existed to reduce the sharing and repeat use of needles, rather than to act as a pure exchange service. The free availability of needles and equipment also meant that they had very limited resale or cash value.

The approach pursued within Leeds had been successful: there were fewer than 10 injecting drug users with HIV within the city. Locating the facility in *Boots* had been successful in reducing stigma and enhancing accessibility.

Although there had been problems initially with anti-social behaviour, the store had developed its needle exchange provision into a more specialised service in the downstairs of the store, which had improved relations between users of the service and general customers. It had shifted from being a store which was 'black marked' by national management to a successful enterprise.

B. Leeds General Infirmary

Epidemiology

Dr Mike Gent, Director of the West Yorkshire Health Protection Unit, gave a presentation on the epidemiology of HIV in the area. In 2009 there had been 391 new HIV diagnoses in Yorkshire and the Humber; this represented a 255% increase from 2000 levels. 56% of the diagnoses were classified as late (a CD4 count at diagnosis of less than 350 cells per mm³ at diagnosis) and 32% were very late (a CD4 below 200 cells per mm³).

HIV was more prevalent in urban and deprived parts of the region; areas showing increased prevalence over the past decade had a strong correlation to those areas which had received dispersed asylum seekers. Over 50% of the local HIV-positive population were heterosexual black Africans, although the greatest percentage increase in diagnoses over recent years had been amongst white heterosexuals.

The geographic variation in prevalence was also of note. Although Leeds overall had a prevalence below 2 per 1,000—the rate at which national guidelines recommend expansion of testing programmes—there were areas within the region where prevalence exceeded that level. There were questions, therefore, around how testing expansion was to be approached in the light of this variation.

However, monitoring of new diagnoses showed that rates of recent infection were higher amongst men who have sex with men, with more than 50% of those newly diagnosed in Leeds and Sheffield recently infected. This suggested higher levels of new infections amongst that group. It was imperative to continue the roll-out of RITA testing in order to better understand transmission patterns.

A significant proportion of the patient cohort was aged over 50. Given the increased levels of vascular and neurocognitive issues in this group, the engagement of GPs in their care was crucial.

North and West Yorkshire HIV Network

This was followed by a presentation from Dr Eric Monteiro, a consultant in Genitourinary Medicine at the Leeds Teaching Hospitals, setting out the work of the North and West Yorkshire HIV Network. The network was centred around ‘principal treatment centres’—Leeds had been ‘pre-designated’ as one such hub. Facilities in York, Scarborough and Wakefield acted as satellite units, referring complex patients to the centre and utilising centralised expertise in patient management.

The network, established in 2010, provided services to over 2,200 HIV positive patients across these centres. Joint service and care specifications had been developed, and the network provided a forum to share expertise and facilitate joint working across the region. Unlike other similar care networks, however, the HIV network had no identified funding stream or administrative support. Funding levers were required to more firmly establish the model, particularly in the light of concerns over commissioning reforms.

It included representatives from hospitals, public health services and commissioners, as well as community and patient organisations, and had developed a number of protocols for care and agreed work streams for use across the network. These work streams covered areas such as early diagnosis in acute settings and community HIV testing, as well as pre- and post-exposure prophylaxis. The representation of community groups sought to engage the network with prevention issues as well as those around treatment. Primary care needed to become more engaged and involved in the work of the group.

HIV care in District General Hospitals

Dr Lindsay Short, GUM Consultant for the Calderdale and Huddersfield NHS Foundation Trust, spoke about the nature of care provided in smaller centres.

Positives

District hospitals offered a number of advantages: for one, services could be provided closer to patient's homes; and owing to smaller team sizes, strong patient-clinician relationship could be developed. Indicators, such as high levels of patient retention, suggested high levels of patient satisfaction. The development of the North and West Yorkshire HIV network had built upon these strengths, developing clinician links that allowed the discussion of difficult cases and supported patients if they needed to be transferred to more specialist facilities.

Challenges

Delivering care in district settings was not without challenges. There had been a rapid increase in the cohort: Huddersfield Royal Infirmary had gone from 24 patients in 2001, to 182 in 2007 and 330 in 2011. This brought pressures for a small clinical team, which had not enjoyed a corresponding increase in resources or capacity. A policy which discouraged consultant-to-consultant referrals only made this worse. Furthermore, not all district settings had access to a HIV pharmacist or psychosocial services, both of which were essential to providing effective care.

In logistical terms, the provision out of hours care was also sometimes difficult, and IT support was insufficient to cater for service innovations. There were also problems around the transparency of budget provision.

The development of the regional HIV network would be vital in allowing North and West Yorkshire to respond to these challenges. It would allow patients to continue to receive their care as close to home as possible, whilst also developing capacity across different centres and facilities. It was unclear how proposed NHS reforms would impact upon this evolution of services.

There were also concerns around any over-centralisation of specialist care. It was important for clinicians in district hospitals to continue to be exposed to and deal with complex and specialist cases, in order to develop their knowledge and skills around HIV. As well as this, GPs had to be encouraged and reassured about involvement in patient management, and patients encouraged to involve primary care in their treatment.

Sexual Health Research in York

Dr Fabiola Martin, Senior Lecturer in HIV Medicine at Hull York Medical School briefly presented information on current HIV research initiatives. The school was currently involved in a number of research initiatives focused upon prevention methods, including microbicidal gels, rings and mucosal vaccines, as well as research aimed at better understanding the activity of antiretrovirals. Future research planned in the centre included oral antiretroviral HIV prevention studies in MSM and more detailed work upon anti-HIV microbicides.

It was important to understand the effect and performance of these initiatives upon women, who were at greater risk of STI acquisition and were often disempowered within sexual relationships. Research also highlighted the difference between efficacy and effectiveness, with major differences between perfect and typical use of most prevention interventions.

Management of HIV at Leeds Teaching Hospitals

Dr Jan Clarke, Consultant in Genitourinary Medicine, gave a presentation on how HIV was managed at the hospital.

Workload

The patient cohort at the hospital had increased from 271 in 2002 to 1137 in 2010, a 195% increase. Around 70% of patients were dealt with in GUM services, with the rest dealt with as part of the infectious diseases cohort. Care for young people and families, as well as antenatal care, were areas of priority, but so were the challenges thrown up by an ageing HIV cohort

Staff profiles

There were three categories of staff involved with HIV services at the hospital: HIV-specific staff, such as clinical nurse specialists, pharmacists and midwifery coordinators; staff with HIV specific components in their job plans; and supporting staff, including health advisers involved in partner notification.

Service configuration

The Trust was one of four designated centres for complex HIV care in Yorkshire and the Humber. This was part of the development of a HIV network within the region. Spending on HIV was around £10m per year—around 1% of an overall £1bn Trust budget.

Service delivery was split over two sites, located 15 minutes apart. Outpatients were dealt with at Leeds General Infirmary, with HIV inpatients and infectious diseases outpatients dealt with at St James's. This disconnection made service provision more difficult and merging was an issue to be discussed.

Given the development of a network, it was imperative to work more effectively in combination with services elsewhere. Virtual clinics, where clinicians could share their expertise via telephone or online, was one potential development. Another was the establishment of pathways to devolve care elsewhere, with specialist oversight. To do so, however, required a more effective IT network than existed at present. Across all areas, it was important to improve the patient experience to ensure engagement with services, for example through greater availability of appointments.

Benchmarking

There were a number of methods by which services were benchmarked. At PCT level, there was a CQUIN commissioning benchmark regarding access to care, and services were audited in line with BHIVA standards. Both demonstrated that services were effective. At a commissioning level, the Yorkshire and the Humber Specialised Commissioning Group benchmarked services through the use of year of care tariffs, common standards and care pathway agreements.

Clinical issues

Access to testing

It was important to increase access to testing services, especially in non-specialist settings. Staff, not patients, had been shown to be the barrier. To effect change, it was important to gain the support of team leaders to influence behaviour throughout the hospital.

A poster campaign was underway within the hospital aimed at acute medical staff, and influence was brought to bear on staff from elsewhere in meetings with other

departments. Staff hoped that this would boost testing levels when patients presented with indicator diseases, an area for improvement which could reduce levels of late diagnosis.

Partner notification

Partner notification was an important strand of prevention. However, it was a difficult area to secure resources for, as there was no standard metric by which to audit the work done. Nonetheless, it was an area that needed focus.

Capacity

Capacity was a problem. Despite increasing patient numbers, it was felt that staff resources had not risen commensurately. In 2011, for example, funding was only available to make use of one of the unit's specialist pharmacists part-time. This increased the pressure on staff.

Psychological services

Psychological care services were insufficient. It was "amazing" that there was no in-house psychological provision, given the role that such services could play in clinical care.

Primary care

Expanding testing into primary care was important. As part of those efforts, the Trust had established a website offering leaflets and guidance for GPs, an important resource for increasing familiarity with HIV.

Infectious Diseases at Leeds Teaching Hospitals

Dr Hugh McGann, Consultant in Infectious Diseases, gave a presentation on how HIV inpatient services were managed at the St James's Hospital facility, part of the Leeds Teaching Hospital Trust.

Cohort

There were 374 patients in the cohort at St James's, with an approximately even split of men and women. Most patients were diagnosed late, often following a visit to the unit with an opportunistic infection. More than 50% were diagnosed with a CD4 count below 200 cells per mm³, and a significant proportion of patients had a CD4 count below 50 cells per mm³. Such patients were "extremely" expensive to treat as a result of prolonged hospital stays.

Capabilities

The unit contained 18 beds, with four negative pressure suites for the containment of infectious patients. It was staffed by infectious disease consultants along with a specialist HIV pharmacist and nurse specialist, and nursing staff with experience of dealing with HIV infections. Staff met weekly alongside staff from GUM services to discuss patient management.

HIV testing

Pilots into expanding HIV testing on the ward commenced in January 2011. All patients admitted were offered HIV testing on an opt-out basis, and the uptake rate was 98%. Staff hoped that this success would lead to expansion of the policy into acute medical settings. HIV testing was also offered to all patients with active TB.

HIV and pregnancy in Leeds

Dr Alison Perry, Foetal Screening Coordinator, outlined how HIV and pregnancy was managed at the Trust.

Cohort

In 2009, approximately 50 HIV-positive women gave birth at the hospital; fewer than 10% of deliveries were by Caesarean as a result of viruses in the bloodstream. Success was down to monthly multidisciplinary team meetings where each patient's plan was discussed and agreed. Peer interaction of this kind encouraged staff learning and meant that the service could mature through experience.

Challenges

Syphilis had emerged as an issue at the hospital. As a result, its management had become an element of care to be arranged and discussed as part of team meetings.

As well as medical challenges, there were multiple logistical obstacles. Women often used multiple names to protect their identities; and in contrast, there was evidence that a single identity had been used by multiple women. Such practices, along with dispersal of women to other areas, made close follow-up and long-term patient relationships difficult.

Other issues were cultural. Communities often stigmatised women who did not breastfeed; this posed an obstacle to best practice, and the lack of milk tokens for women hampered efforts even further. Women were also often fearful of partner notification, which further inhibited prevention efforts.

Paediatric HIV services

Dr Amy Evans, Consultant in Genitourinary Medicine, talked to the Committee about paediatric HIV services in Leeds. There were 41 children or young people involved in the service at present, of whom the largest proportion were aged between 11 and 15. Within the service, there was a paediatric consultant, a paediatric HIV clinical nurse specialist, a paediatric pharmacist and a GUM consultant. All staff were only involved part-time.

Children's HIV network

There was a well-established national clinical network in the United Kingdom. However, Leeds was incorrectly classed as a 'local centre', despite the fact its cohort was large enough to classify it as a regional network 'hub'. If correctly designated, the service would have more (and full-time) staff; as it was, it was outgrowing its configuration.

Management of children

Services were delivered through two consultant-led clinics and one nurse-led clinic each month. As part of those clinics, a family and young person's service, transitional care for young people and alternative access to HIV care and testing were all offered. The primary challenge was providing the full range of services with a staffing level "insufficient" for the size of the cohort.

HIV testing

The hospital sought to get all children of HIV-positive parents tested, as part of the Children's HIV Association campaign, 'Don't Forget the Children'. Although numbers were small—two children out of 46 tested positive in 2010—staff asserted the need to remain vigilant.

Developments

There were a number of developments in progress for the service, centred on improving care for young people. An adolescent forum, which sought to develop the provision of transitional care, was one. Others centred on more flexible clinics, individual transition plans for patients and broader guidelines for the management of transitional care.

More broadly, there was close working between Yorkshire and the Humber's HIV network and the Children's HIV National Network to integrate services where possible. Collaboration of that kind was essential for the unit, as a small service struggling to adapt its infrastructure to an expanding cohort.

HIV clinical nurse specialist

Anna-Luisa Simonini outlined the role of the HIV clinical nurse specialist in genitourinary medicine services at Leeds. In Leeds, the nurse specialist ran a nurse-led clinic on a daily basis. This involved, amongst other tasks, adherence management of a diverse cohort of patients, sexual health screening and liaison with the multidisciplinary team for onward referral where necessary.

Recent infection data at the Leeds Centre for Sexual Health

Dr Sarah Schoeman gave a presentation to the Committee on the results of a survey of rates of recent acquisition of HIV in MSM attending the Leeds Centre for Sexual Health.

Recent infections

The Recent Infection Testing Algorithm (RITA) had been introduced as a routine test for newly diagnosed HIV patients from November 2009, and allowed staff to investigate trends in HIV infection.

Results from 78 new HIV diagnoses over 12 months showed that 35% of infections acquired from sex between men occurred less than five months before the diagnosis. This was nearly twice the UK average of 17%. Between August and September 2010, an even higher proportion—56%—were recent diagnoses. For heterosexual transmission, levels, at 2.6% (1 diagnosis out of 78) were below the UK average of 7%. Amongst all those recently diagnosed, 43% were co-infected with Chlamydia and 29% were co-infected with gonorrhoea.

Such sophisticated data provided an opportunity to take action amongst MSM where rates were disproportionately high. Interviews with the cohort revealed common risk taking behaviours. After liaison with the Health Protection Agency and Yorkshire MESMAC, the Trust delivered materials to the local MSM population, and continued to monitor RITA results. Use of such data to track transmission trends and raise awareness of risk levels would be important in future.

Question and answer session

Representatives from the hospital took questions from the Committee across a number of areas.

Sex on premises venues

The Committee asked about tackling HIV transmission within sex on premises venues. Staff noted that such venues were increasingly private, a trend accelerated through the emergence of social networking as a facilitator.

However, staff were keen to note that such behaviour did not reflect MSM being ‘jaded’ around HIV. Instead, those infected often led chaotic lifestyles or suffered from misconceptions around risk. Lack of information—particularly in relation to ‘serosorting’, where MSM sought out same-status partners—was a much greater concern than any indifference to HIV.

Charging regulations

Clinicians were not positive about the concept of charging for HIV care for those not lawfully resident in the United Kingdom. They stressed that there was no evidence of health tourism, and that it was treating patients was cost-effective for public health reasons. As a result, it was the policy of the hospital not to ask patients about their background.

Late diagnoses

The Committee asked about the implications of late diagnosis. In response, staff highlighted the high rates of short-term mortality, and the fact that the long-term prognosis was not as good as for those diagnosed early. In addition, it was noted that admissions following on from late diagnoses were also “very, very expensive”.

C. Leeds Skyline

Sinead Cregan, Adult Social Care Commissioning Manager in Leeds, introduced a session with staff members at BHA Skyline, a community organisation which delivered both HIV prevention services for African communities and support services for a broad range of those living with and affected by HIV. Those present included Jeni Hirst, BHA Director of Sexual Health and Rebecca Bryan, Project Coordinator.

Integrated services

The aim of Skyline was to commission support and prevention services together, with pooled budgets to do so. Staff felt that this integration had been achieved; funding was provided by Leeds City Council for social support services, whilst NHS Leeds part-funded preventions services tailored for African communities.

Support services

Support services began with an initial assessment of need, following which a care plan was drawn up and subsequently reviewed every 12 weeks. The service user then took part in interventions aimed at meeting the needs outlined in the care plan. Interventions took a variety of forms, from intensive one-to-one and group support through to workshops, training and advocacy. Support was often tailored; for example, there were specific work groups aimed at, amongst others, women, black African MSM and young people. These attended to physical, social and psychological needs.

Physical

Staff at Skyline “filled in gaps” that consultants at the hospital did not have time to cater for, such as complementary therapy for side-effects. In light of this role, Skyline staff attended weekly meetings at the hospital to ensure clear referral pathways through to Skyline (although referrals also came from primary care and from walk-in patients).

Social

The provision of support for service users seeking to return to work was a prominent element of Skyline’s work; service users present for the Committee’s visit commented specifically upon it. Support involved workshops around disclosure to employers and CV and interview tips. Some social care needs, though, were beyond the expertise of Skyline staff, and so referral to external services providing housing, benefits or employment advice was an important element of the overall package of interventions.

Psychological

Support was wide-ranging, including guidance around disclosure, stigma and risk as well as community outreach work to combat isolation. Confidence and skills were built up, improving patient self-management. Work around adherence to antiretroviral therapy was particularly significant, and users positively commented on the help provided by Skyline in navigating clinical services.

Mental health services were prominent. Much of the work was delivered through peer support, which feedback suggested was more informal and personal. One service user referred to such services as “invaluable”.

Prevention services

Transmission profile

Over time, there was an increasing level of transmission amongst black African communities within the United Kingdom. Although the numbers of asylum seekers dispersed to Leeds had decreased, there were still many students from African communities. It was important to determine the level of transmission in this group, as the increase in UK-based black African transmission demanded a shift in how prevention services were organised.

Funding

Prevention work aimed targeted at African communities was funded through the National African HIV Prevention programme, Department of Health-funded national prevention programme commissioned by the African Health Policy Network. Alongside general prevention interventions, Skyline staff were funded to operate an HIV information line for African communities.

Targeting

Although dispersal levels had fallen, there was still a prominent African community in Leeds which required targeted attention. Work was targeted at those living with HIV, people in relationships where one partner was HIV-positive, those involved in high-risk behaviours or partners of those who were.

Despite involvement in the NAHIP programme, staff insisted that the targeted approach to prevention needed to be considered in light of growing epidemics outside of African communities and MSM. It was also important to think about young people, particularly as new generations of immigrant communities became sexually active.

Aims

There were a number of aims for the prevention work at Skyline: a reduction in the number of new HIV infections amongst African communities; a reduction of the prevalence of undiagnosed HIV; challenging stigma; and the empowerment of people to engage with care to increase testing and treatment levels. Secondary prevention—the prevention of onward transmission from those already infected—was an important facet of such work.

Activities

Activities were delivered in the community; work involved workshops and training, campaigns, information provision, community events and skills building. Along with such capacity building, the distribution of safer sex resources—in particular condoms—was vital.

Model

Prevention interventions were guided by a NAHIP-produced service model called *The Knowledge, the Will and the Power* (KWP). It consisted of three strands: knowledge, which related to information provision; will, which was linked to ending unsafe behaviours by challenging societal norms, and outlining to people the cost-benefits of avoiding HIV infection; and power, which involved building up skills and confidence to allow people to protect against HIV infection.

Barriers

Stigma was still a significant barrier to the delivery of HIV prevention and support services. Work needed to be done at all levels, as were social attitudes around issues such as homosexuality, driven by cultural and traditional beliefs. More practical factors in relation to immigration status and social and economic circumstances—particularly the number of languages spoken within African communities—also played a part.

Faith

Staff at Skyline had found it difficult to make inroads into faith communities. Meetings had been organised with church leaders and Skyline staff offered their services but often, especially in Pentecostal churches, such offers were refused. There was much work to be done, particularly around the reality of HIV and the importance of adhering to treatment.

Funding

The local authority had been convinced to use its entire AIDS Support Grant (ASG) allocation to support Skyline. With lobbying from some commissioners within the local authority and from those within the Skyline service, local authority provision had increased from £70,000 when first funded to more than £500,000 at the time of the visit. There were commitments for both NHS and local authority funding streams to continue for at least another two years.

Such support did not mean, though, that Skyline had been immune from funding pressures. Funding for some physical treatment services had been withdrawn by the NHS, and provision was maintained only after social services commissioners provided funding for what was traditionally an NHS competence.

National work

As well as the provision of regional support and prevention services, Skyline fed into national evidence-gathering, research and policy processes. As part of the NAHIP prevention programme aimed at African communities, it also fed into the structuring of prevention work nationally.

D. Yorkshire MESMAC

MESMAC was a community-based voluntary organisation offering a range of sexual health services, primarily targeted at MSM. These included the delivery of HIV prevention campaigns, community based testing, group work, counselling, professional training and outreach work. The organisation had multiple funders, including the Department for Health-funded Community HIV and AIDS Prevention Strategy (CHAPS). The service operated across Leeds, Bradford, North and West Yorkshire.

Prevention

HIV prevention was delivered through a number of channels. Of particular importance was group work, which allowed members to reflect on common concerns and develop strategies to promote safe sex. MESMAC operated a range of different groups including sessions for black MSM deaf men, transgender people and older men. The deaf men's group had been established to deliver niche provision to a group who often had difficulty accessing and interpreting mainstream prevention messages.

Group work was supplemented by campaigns in the local press and through local gay media, as well as new delivery methods such as podcasts. Recent campaigns had included adverts to promote the use of post-exposure prophylaxis.

MESMAC also ran a dedicated project (entitled BLAST) which sought to support young men and boys at risk of being sexually exploited. This programme, which dealt with 3,000 people each year, had been established as a response to growing concerns about the use of internet sites to exploit young people. The programme consisted of school visits, promotional materials and online content.

Outreach

Outreach work was intended to promote services, such as community testing, in environments where service users felt comfortable. In addition, outreach work sought to meet the needs of those who 'fell through the net' of existing provision. MESMAC was involved in outreach work in clubs, saunas, public sex environments, prisons and churches.

Through direct engagement in these settings, the community and voluntary sectors could add value to the work of health and professional services. Outreach also provided a channel for immediate feedback and evaluation of services, given the direct engagement with service users.

MESMAC staff were asked about prevention work in prisons. They said that the nature, extent and success of work varied enormously, according to the approach of individual governors and the culture of different prison settings. Some prisons had condoms freely available on wards; others provided them only after an approval process. No needle exchange facilities, to their knowledge, operated in prisons. To support health promotion work in prisons, MESMAC had recently produced a DVD toolkit for prison officers, to assist them in dealing with HIV.

Testing

MESMAC offered community-based testing at a city-centre venue. This was primarily aimed at MSM and operated on a self-referral basis, with a Thursday evening drop-in clinic and an 'as and when' service for the remainder of the week. Tests were delivered by non-clinical staff and results were available within 20 minutes. One advantage of delivering tests in this setting was that non-clinical staff

typically had a greater amount of time available for both pre- and post-test discussions, as well as health promotion advice.

A service user who had tested positive for HIV gave an insight into his experience of using the service. He had felt more comfortable going for a test in a community setting, believing that it would be easier to discuss his circumstances and background with non-clinical staff. After testing positive, he had found the post-test support from MESMAC “invaluable”, allowing him to consider his health needs and develop an approach for discussing his condition with family and friends. He had also been supported in dealing with employers who had terminated his contract following ill-health post-diagnosis.

Counselling

MESMAC had access to 32 qualified counsellors covering the whole of North and West Yorkshire. Spot purchasing arrangements for this support allowed them to buy time from different counsellors as and when required. This made for a flexible service, allowing them to respond to the individual needs of different users. The approach was in fact so flexible that counselling could be provided in six languages, including British Sign Language.

Conclusion

Health promotion around HIV had become more difficult over the past 20 years, as the condition was now far less “visible”. Many MSM, particularly of the younger generation, were found to believe that they had not met anybody with HIV; it was therefore difficult to strike the appropriate balance between stressing the efficacy of treatment and highlighting the risk and impacts of transmission. Throughout all prevention work, there was a need to avoid stigmatising people with HIV.

APPENDIX 7: VISIT TO HMP BRIXTON 17 JUNE 2011

The Committee visited Her Majesty's Prison Brixton. Lord Fowler, Lord Gardiner of Kimble, Baroness Healy of Primrose Hill, Baroness Hussein-Ece, Baroness Masham of Ilton and Lord Rea were in attendance.

Introduction

The Committee were given a tour of the prison and its healthcare facilities, which were “out of date” as the prison was a Victorian-era construction. The Committee then met the governor of the prison, Ed Tullett, and its healthcare manager, Dr Taps Mutakati, for a discussion on HIV and related issues within the prison.

The Committee would like to thank both Mr Tullett and Dr Mutakati, and all of those involved on the day, for their work in arranging activities on the day and for their time in providing information to the Committee.

Healthcare services

Commissioning

It was explained that healthcare services for the prison's 798 inmates (of whom half were remand prisoners) were commissioned by the local Primary Care Trust through Care UK, a private provider. Services were commissioned to be at an equivalent level to healthcare in the community. The PCT spent £6m on health services, compared to the £20m spent on all other operations in the prison. Taken together, this meant that healthcare made up nearly a quarter of money spent on services in the prison overall.

Prisoner screening

Prisoners were assessed on entering the prison for mental health problems and drug dependency. HIV was not tested for at that point; patients were referred to the blood-borne virus (BBV) clinic if a test was desired. Approximately 50% of those entering the prison requested one, but around 30% of those who did failed to fulfil their appointment. Tests could also be offered and recommended if risk factors were determined or symptoms were raised during subsequent engagements with healthcare staff.

The issue of routine opt-out testing was raised. There was no real argument against it in prisons, provided that there was informed consent; it offered the potential to destigmatise testing and increase its uptake. The only concern related to timing. Dr Mutakati felt that prisoners needed time to settle before testing, but acknowledged that there was a risk that inmates could be lost to the system if testing was delayed.

Prevention services

A counselling service was available to talk about risk factors for HIV, which was part of the prevention programme in the prison. There were also health promotion campaigns on a number of topics, and further opportunities for health promotion when patients attended the blood-borne virus clinic.

Condoms were also available through an application form or through an appointment at the sexual health clinic. Requests could be traced, but confidentiality was seen as important. The process was required because condoms were used for swallowing drugs; staff said that they could not “risk them hanging around”. Demand, however, was low, and requests were often several months

apart. As a result, there was little appetite for change to the existing model of provision.

HIV management

There had initially been a fear of HIV within prisons. Now, HIV presented “minimal difficulties” for prison staff. There was, though, anecdotal evidence of stigma. It was claimed that an inmate had been refused work in the kitchen because of their HIV-positive status.

The 11 HIV-positive prisoners in Brixton were not separated from other inmates, and they were managed in the same manner as those with other infectious conditions such as TB. A specialist HIV consultant and trained nurse practitioner attended the prison once a fortnight. Antiretroviral drugs were provided for those patients (9 out of the 11) who were on a course of treatment. The pharmacy had procedures in place to ensure people who entered prison already on treatment were able to continue their regimes with as little interruption as possible.

Drug use

Drugs were a problem in society as a whole, and this was reflected in the prison. There were examples of inmates significantly shortening their lifespan through drug abuse, and 100 prisoners, one in every eight, were on opiate substitutes such as methadone. However, only 5% of the population were found, using random sampling, to be using drugs; a “good level” for an inner-city prison.

Treatment programmes were available for those with drug dependencies through the integrated drug treatment service in the prison’s ‘detox’ unit. Strategies for controlling blood-borne viruses linked with those for substance misuse; on entry, a HIV test was offered if the inmate had not been tested in the previous four months. Looking forward, there was a plan to pilot a drug recovery wing, with a focus on drug abstinence.

Needle exchange

Needle exchange programmes were not supported. For one, injecting drug use was at a low level; most drugs were smoked—the greatest risk of needle sharing came from homemade tattoos. Furthermore, it was felt that needle exchange programmes would “condone” injecting drug use, and would be very unpopular amongst staff. The focus had to be on abstinence, curing the dependency of prisoners.

APPENDIX 8: GLOSSARY

Key organisations referenced in this report

African Health Policy Network (AHPN):

The African Health Policy Network is an umbrella organisation of mostly African-led community based organisations that acts as a collective voice for African communities on HIV and sexual health. Like THT, the AHPN is commissioned by the Government to deliver part of the national prevention strategy, administering the National African HIV Prevention Programme (NAHIP). It acts as an advocacy group, whilst also conducting research into HIV policy.

British Association for Sexual Health and HIV (BASHH)

BASHH is a professional association in the field, with membership drawn from medical practitioners, medical scientists and other healthcare workers specialised in the field.

British HIV Association (BHIVA):

BHIVA represents professionals in HIV care. It acts as a national advisory body, working with a number of actors in the field to produce national audits, clinical guidelines and other research.

Health Protection Agency (HPA):

The HPA are currently responsible for surveillance of HIV in England, and work with similar devolved bodies to monitor the epidemic nationwide. Under reform proposals, this work will take place within Public Health England.

Medical Foundation for HIV and AIDS (MedFASH):

MedFASH is a charity “dedicated to the pursuit of excellence in the healthcare of people affected by HIV”.⁵⁵⁰ MedFASH develops information and guidance for practitioners and conducts evaluative research into HIV policy.

National AIDS Manual (NAM):

NAM produces resource materials to disseminate information about HIV policy and research. Funding for this work is received from a variety of sources: it has been commissioned by the Department of Health and the NHS to produce information on a variety of issues, alongside work funded by charitable foundations and trusts.

National AIDS Trust (NAT):

NAT is a leading charity “dedicated to transforming society’s response to HIV”. An organisation focusing mostly on policy rather than service delivery, it describes its outlook as “independent and evidence-based”.⁵⁵¹

Terrence Higgins Trust (THT):

THT are a prominent HIV and sexual health charity who are commissioned by the Government to deliver the Community HIV and AIDS Prevention Strategy partnership (CHAPS), part of the national prevention strategy aimed at men who have sex with men. It also produces information materials for those with HIV, and conducts research into areas of HIV policy.

Important terms used in the report

Antiretroviral therapy

Antiretroviral therapy is the current method of HIV treatment. Such therapy cannot cure HIV, but it can slow its progress. Antiretroviral treatment involves

⁵⁵⁰ <http://www.medfash.org.uk/>

⁵⁵¹ www.nat.org.uk

taking a combination of drugs which work against HIV. These aim to reduce viral load to undetectable levels.

Black African

The term black African is used in relation to the ethnicity or ethnic group identified by a patient when data is collected.⁵⁵² The term 'black African' includes anyone who identifies themselves as such, whether they are migrants from Africa, African descendants or African nationals. Black African communities encompass diverse population groups including people from a range of cultural, ethnic and faith backgrounds who may be heterosexual, bisexual or homosexual.⁵⁵³ The black African community are the demographic second-most affected by HIV in the United Kingdom, after men who have sex with men.⁵⁵⁴

CD4 count

This is a count of a certain kind of white blood cell in the body, which HIV attaches to, infects and can destroy. Doctors test for the number of CD4 cells in a cubic millimetre of blood. This measure gives an indication of the impact of HIV on the body's immune system. Treatment guidelines recommend that treatment begins when the CD4 cell count drops to 350 cells per mm³. The rate at which CD4 cells are lost varies, but it may be several years after infection before treatment is needed under existing guidelines.

Incidence

Incidence refers to the number of new infections in the population during a certain time period. Most often, incidence is measured in terms of numbers of infections in a year. As those infected with HIV often do not display symptoms immediately, diagnosis can come months or years after infection. This makes measuring of the incidence of HIV a difficult process.

Infectivity

Those with HIV can potentially pass on the virus to others through blood, semen and vaginal fluids. HIV is thus passed on through unprotected sexual intercourse, sharing of contaminated injecting equipment, from mother-to-child during pregnancy or breastfeeding, and from infected blood and blood products. The measure of the ability of a person to pass on the virus is known as infectivity, which is linked to their viral load. As HIV treatment reduces the amount of HIV in the body, it can therefore reduce the likelihood of an infected person passing on their virus, and thus reduce infectivity.

Late diagnosis

Late diagnosis is a measure recorded by the HPA in relation to the CD4 count of an individual within the first three months of diagnosis. Treatment guidelines recommend that treatment begins when the CD4 count of an individual falls to 350 cells per mm³. If an individual already has a CD4 count below this level within three months of being diagnosed, this is considered to be a late diagnosis, as treatment should already have begun.

Very late diagnosis is measured in relation to previous treatment guidelines, which recommended that treatment should begin when CD4 counts fall below 200 cells per mm³. If an individual's CD4 count falls below that level within three months

⁵⁵² HAUk 97 (Health Protection Agency)

⁵⁵³ NICE public health guidance 33: increasing the uptake of HIV testing to reduce undiagnosed infection and prevent transmission among black African communities living in England; and NICE public health guidance 34: increasing the uptake of HIV testing to reduce undiagnosed infection and prevent transmission among men who have sex with men. Both published March 2011

⁵⁵⁴ HPA, HIV in the United Kingdom (2010 Report), *op cit.*

of their initial diagnosis, this means that treatment has been significantly delayed, and therefore the diagnosis is considered to be very late.

Men who have sex with men

Men who have sex with men (MSM) is a designation used to describe a demographic of people who are at greatest risk of HIV infection within the United Kingdom, given the relatively high risk of HIV infection from unprotected anal intercourse. MSM are a socially and culturally diverse group, some of whom may not self-identify as 'gay'.⁵⁵⁵

Opt-out testing

Opt-out testing is a manner of offering and recommending a test to a patient. A clinician informs a patient about the nature of the test to be performed, which takes place unless the patient refuses. This contrasts with opt-in testing, where a patient must indicate their willingness to be tested, without which a test is not performed.

Post-exposure prophylaxis

Post-exposure prophylaxis is a short course of antiretroviral treatment taken after potential exposure to HIV, such as through unprotected sex or the sharing of drug injecting equipment, with somebody who is known or suspected to be HIV-positive. It has been used for many years to protect healthcare workers who have had possible exposure to HIV, for example after accidentally pricking themselves with needles used on people who were known to be HIV-positive or at risk of HIV. Guidelines produced by professional bodies state that it should be provided within 72 hours of the possible HIV exposure.

Pre-exposure prophylaxis

Pre-exposure prophylaxis refers the use of antiretroviral drugs prior to exposure to the virus. It is thought that this may have a preventive effect. A recent high-profile trial found that the HIV infection rate in HIV-negative gay men taking a daily preventive pill containing two HIV drugs was reduced by 44%, compared with men taking a placebo.⁵⁵⁶ The possible use of pre-exposure prophylaxis as part of a strategy to reduce the spread of HIV is an area of increasing interest in the research community.

Prevalence

Prevalence refers to the proportion of people in a given population who have acquired a specified infection at a point in time, regardless of when they first acquired the infection. If one person in a group of 100 was infected with HIV, for example, prevalence can be expressed either as 1% or as 10 people per 1,000. For HIV, prevalence figures produced by the HPA include the number of people diagnosed as well as undiagnosed.

Public Health England

Public Health England is a proposed dedicated public health service for England, envisaged as part of Government NHS reform proposals. It is intended that it will have a ring-fenced budget in order to both coordinate local work and manage national public health concerns.

Viral load

Viral load is a measure of HIV in the blood. It is an estimate of the number of HIV particles in blood plasma, and is measured in terms of numbers of copies of HIV

⁵⁵⁵ Health Protection Agency, Men who have sex with men:

<http://www.hpa.org.uk/web/HPAweb&Page&HPAwebAutoListName/Page/1202115502896>

⁵⁵⁶ Grant RM *et al.*, *Preexposure chemoprophylaxis for HIV prevention in men*. New Engl Jour Med early online edition, 23 November 2010

per millilitre. The greater the viral load, the faster a person's white blood cell count is likely to fall, and the greater the risk of developing symptoms of HIV infection. Treatment using antiretroviral therapy reduces the level of the virus in the blood, and therefore monitoring the viral load is a good indicator of how treatment is working.

The aim of treatment is to achieve what is known as an undetectable viral load as soon as possible. Increasingly sensitive tests mean that viral loads as small as 40 to 50 copies per millilitre of blood can be detected. If therapy reduces viral load below this level, it is considered to be undetectable. Bringing viral load to this level reduces the risk of becoming resistant to drug therapy, as well as reducing the risk of illnesses arising because of a suppressed immune system.

Viral resistance

HIV is a retrovirus, and is able to mutate and reproduce itself inside white blood cells. The ability to do so in the presence of antiretroviral drugs, rendering such drugs ineffective, is called HIV drug resistance. The consequences of drug resistance include treatment failure, increased healthcare costs owing to more complex treatment, the spread of resistant strains of HIV and the need to develop new anti-HIV drugs.⁵⁵⁷

Wellcome Library

⁵⁵⁷ World Health Organisation, HIV drug resistance:
<http://www.who.int/hiv/topics/drugresistance/en/index.html>

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